Silent, invisible and under-supported? An autoethnographic journey through the valley of the shadow and youth mental health in Australia

by

Anne Alexandra Hugo,

B.A., Higher Dip. (Education), Higher Dip. (Librarianship).

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Abstract

This autoethnographic account of personal loss and consequent meaning-making aims to contribute to a unique understanding of young Australians facing both times of uncertainty and mental illness. As a qualitative study, it explores the lived experience of the researcher whose working life was spent in youth studies. This tacit knowledge seemed to fail as she tried to get help for her mentally ill son who died unexpectedly of a drug overdose. Using critical autoethnography and a highly reflexive approach, the researcher deploys three reflexive selves – mother-self, youth studies self, and autoethnographer/researcher-self – in order to answer the research question, *How might a mother's autoethnographic account of her son "falling through the cracks" help us to better understand and support Australian youth experiencing mental illness?*

The study contributes insights from a community perspective about the disjunction between policy promises and service delivery for young people with mental illness in Australia. The gap this thesis fills is methodological by nature, since the autoethnographic voice of a parent is rare in the multidisciplinary contexts of this research. Using youth studies as its theoretical framework, the literature review explores broad themes in youth studies as well as mental health, along with specific themes addressed throughout the thesis such as the experience of exclusion from decision-making, the issues of youth agency and mental illness, shame and stigma, suicidality and psychiatric treatment for mentally ill youth. The autoethnography itself is presented as two distinct chapters, the first tracing a narrative arc through migration, schooling, bullying, giftedness, existential angst, suicidality and mental illness, and the second continuing beyond the death of the researcher's son, exploring

the “broken dialogue” in mental health policy and service settings, laying bare a disjunction between the lay and professional views of mental illness. This thesis will be of interest and relevance for professionals who work with gifted youth as well as parents, teachers, policy-makers and others concerned with the mental health of Australian youth.

Dedication

This thesis is dedicated to the memory of François, or Frenchy as he was known.

Acknowledgments

Much of this thesis is written as if I had lived in a bubble alone with my younger son, but that is due to the methodology being autoethnography and to its case-study-like focus on my younger son, rather than any absence of other family members. I thank my family, and pay tribute to my husband, and to my elder son, his wife and family, to whom I owe a huge debt of gratitude for their immense supportiveness and consistent loving concern with which they surrounded me – as they did for my younger son who is a presence in this thesis even if silent.

I owe a deep debt of gratitude to my academic advisors Dr Sharon Thomas and Dr Kerry Howells: thank you both for your support and wise counsel, your wonderful insightfulness and understanding of my research intentions. I especially thank Dr Thomas for introducing me to the treasures of qualitative inquiry, I have learned immensely from you, and special thanks to Dr Howells for initiating my exploration of autoethnography. I appreciate the time and effort you both expended on this project.

I also acknowledge with gratitude the support of my friends as well as fellow students and staff at the Faculty of Education at the University of Tasmania (UTas). I also wish to acknowledge the support of the UTas counselling service, whom I was obliged by the University's ethics committee to visit regularly for my personal psychological wellbeing while conducting this study.

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Chapter 1

Introduction

I never dreamt my son would die; I had no warning, no intimation. His dying was an event beyond my ken and moved me into a foreign country called grief for many years. I retreated to my study, closed the door.

You are in unfamiliar territory.

There is a book lying open on the table.

You are an open book.

I have come to read you. You are inscrutable.

You tell me to write the ending first.

But that will spoil the story, I say.

It happened like this. On a winter's day, I begin.

No, a summer's day, you say.

Well, it was a winter's day in Hobart.

And a summer's day in Europe, you reply.

Two sides of the same coin:

hope and dread.

Life and death.

You called me on the phone. *Mum!*

I can still hear your voice.

A day later your father rings

to tell me you are dead.

How can that be? What can I do? I said,

walking round and round the white room.

What can I do?

Ten years later, writing this thesis, I read in Alasdair MacIntyre's *After Virtue* (1981) that "I can only answer the question 'What am I to do?' if I can answer the prior question 'Of what story or stories do I find myself a part?'" (p. 216).

On first hearing my story, someone with a son experiencing mental illness and severe depression said I had become "every mother's worst living nightmare" (private communication, 2006). Her wry comment, though seemingly blunt, helped make explicit something of which I was soon to become only too painfully aware: that hearing my story – or even just seeing me – might remind others of the potential for disaster in their own children's lives. Western society flinches at the mention of grief and loss, especially at news of the loss of a child. Yet during the course of writing this thesis no less than five acquaintances of mine from one small town have experienced a loss in some ways similar to mine, interestingly, all migrants to Australia. At one of the funerals where several of these bereaved parents were present, another mutual

friend – yet another migrant – commented to me quietly and with gentle dry humour: *I think I will steer clear of you people, I don't want to join your club!*

This qualitative research is based around an autoethnography that describes my experience of my younger son's mental illness, and my attempt at meaning-making after his death. It is, in terms of Arthur W. Frank's typology of illness stories (2010, p. 118), part disaster story, part chaos story, part restitution story, part quest. Autoethnography as a research methodology will be discussed in Chapter 3, section 3.3; it is used by researchers who wish to "intentionally *highlight* the relationship of their experiences and stories to culture and cultural practices" (Holman Jones, Adams, & Ellis, 2013, p. 22, original emphasis).

While this study uses the relatively new discipline of youth studies as its conceptual framework, it is to the field of youth mental health that the autoethnography ultimately takes us. Along the way, it charts the obstacles in the path to healing posed by broad policy and service delivery problems, as well as the everyday problems such as stigma that those who experience mental illness or substance misuse face, and their invisible pain, shame and *self*-stigmatising feelings. It also portrays a parent's puzzlement in the face of their child's psychological suffering.

1.1 Background

Youth studies is a natural frame for me to use as I had spent years working as information manager at the Australian Clearinghouse for Youth Studies – referred to as the Clearinghouse from this point. "Contextual, taken-for-granted, 'tacit knowledge' plays a constitutive role in providing meaning" (Altheide & Johnson, 2011, p. 590) but ironically, at the time, this tacit knowledge did not prepare me when it came to trying to help my son during his mental illness, depression, suicidality and

addiction. I was not prepared for a first-hand experience of what I already "knew" about from youth studies, regarding the lives of young people. This is a study written "from within failure's intensity" (Blanchot, 1986, p. 11) – what I felt had failed was literally my "situated knowledge" as I saw in my own and my son's everyday battles the broader endemic problems in our approaches to supporting youth in Australia. I knew from my work at the Clearinghouse that programs are too often piece-meal, disconnected, short-term, confined to particular groups or regions, that policies are often constructed according to outmoded concepts of young people's lives. I knew about insecure transitions to adulthood, and structural inequalities in funding that perpetuate a broken system. I knew those with both mental illness and addiction problems – or "dual diagnosis" – often "fall through the cracks" (Baker & Kay-Lambkin, 2016; Kenny, Kidd, Tuena, Jarvis, & Robertson, 2006).

Then my son fell through the cracks.

I set out to write a thesis that would answer a question I first formulated as a conundrum: *If it takes a village to raise a child, as an old African proverb avers, then where's the village when the child grows older yet still needs that communal support?* The idea of the proverbial village no longer holds in Western culture: it has seemingly collapsed inwards, into the idea of the individual, and the family. The family is the site of much current policy interest as a source of support for youth who need to establish themselves in work or further study, and to achieve all the other increasingly elusive markers of adulthood like entry to the housing market or family formation, in a replication of all the expected pathways of a previous century's more settled "transitions to adulthood". Chapter 2, *Literature review* is devoted to describing the field of youth studies from both the traditional youth development or transitions model and the youth cultural studies perspectives. The autoethnographic chapters

(Chapter 4 and Chapter 5) describe a personal journey through a story of mental health.

1.2 Aims

The thesis is the distilled scholarly reflection on my story – and my son's – as a quest to find meaning and make sense of my son's life in the wider context of youth mental health. The aims of my autoethnographic research can be viewed, in the spirit of sociologist C. Wright Mills, from a public and from a personal perspective, in the way of "connecting personal troubles to public issues" (Mills, 1959, pp. 185, 187).

> Know that many personal troubles cannot be solved merely as troubles, but must be understood in terms of public issues – and in terms of the problems of history-making. Know that the human meaning of public issues must be revealed by relating them to personal troubles – and to the problems of the individual life. Know that the problems of social science, when adequately formulated, must include both troubles and issues, both biography and history, and the range of their intricate relations. (Mills, 1959, p. 226).

In terms of "public issues", my autoethnographic account serves this study's aim of adding to our understanding of young people with mental illness. In terms of "personal troubles", working autoethnographically allowed me a way to speak, and to let my son's story speak, in a way neither of us could speak at the time of my son's life.

In choosing to write from a personal perspective, I stress that my aim was not to achieve some cathartic or therapeutic purpose for myself by undertaking this research autoethnographically. There are many definitions of autoethnography, a

qualitative methodology (see Chapter 3). Derived from ethnography it uses "the tenets of autobiography and ethnography" to "describe and systematically analyze personal experience in order to understand cultural experience" (Ellis, Adams, & Bochner, 2011, p. 273).

1.2.1 How this study seeks to contribute to knowledge and theoretical reflection

To accomplish my aim, I trust in the persuasive power of both qualitative inquiry and autoethnography to show how the life and death of this one young man, in the words of Ron Pelias, "might matter to a given community, how telling a personal story might function in the social world, how sharing a tale might do needed cultural work" (2015) that might be useful to the lives of those living with mental illness.

A study can make a significant contribution to knowledge heuristically, in terms of how the study might be taken up in the future by other scholars or it might do so methodologically, in terms of how a study looks at an issue in new ways. The gap this thesis seeks to fill is methodological by nature, since the autoethnographic voice of a parent is rare in the multidisciplinary contexts of this research.

This is a study *from* a mother, not *about* a mother, looking at the experience of youth mental illness from a mother's perspective. Wall (2006) – drawing on Denzin and Lincoln (1994, p. 17) – believes that autoethnography can "allow for the production of new knowledge by a unique and uniquely situated researcher" and "offer small-scale knowledge that can inform specific problems and specific situations" (p. 4), and this belief helps bolster my claim for this study's contribution to knowledge.

The concept of cultural criticism and theoretical reflection is a criterion for evaluating experimental writing like autoethnographies if they are a "vehicle for thinking new sociological subjects, new parameters of the social" (Clough, 2000, p.

290; Denzin, 2010a, p. 155). On that basis I trust my study might work as a piece of cultural criticism where theoretical reflection on the autoethnographic text might prompt action in education and policy settings where youth, and mentally ill youth in particular, are at the centre of concern. Much of this thesis is aimed at contributing to the work of talking across the borders of the very different disciplines of knowledge that seek to improve the lives of young people.

1.2.2 The reflexive self as the research tool

My life experience has provided me with three reflexive positions from which to address my research question. First, my older, "youth studies self" had considerable insider knowledge about a field of inquiry germane to the subject matter of this thesis. The second perspective is simply that of a mother – insider knowledge in a family context crucial to answering my research question. The third perspective is my methodological, "present tense" self – an "autoethnographic self" that evolved in the actual writing of this thesis. For deploying all these "selves" in this study, I relied on key authors in qualitative research (Gergen & Gergen, 1988; Harris, 2016; Meerwald, 2013; Peshkin, 1988, 2001). Their ideas of reflexivity and voice helped me speak in a scholarly way into multidisciplinary contexts in order to explore my research question: *How might a mother's autoethnographic account of her son "falling through the cracks" help us to better understand and support Australian youth experiencing mental illness?*

1.2.3 "Writing as a method of inquiry"

To avoid my autoethnography sounding like a monologue, I have used a dialogical approach that includes unattributed direct speech, and extracts from my younger son's poetry as well as my own, believing that "every act of speech or writing has a poetic dimension" (Tedlock, 1999, p. 155) and that poetry can

contribute to meaning-making and to being concise. This also follows Abbott's (2007) plea for "the lyrical impulse" to be present in research writing, since an image, for example can "communicate a mood, an emotional sense of social reality" (Abbott, 2007, p. 73). One crucial image recurs in this thesis, that of a tarnished, grail-like cup, an image that came to me unbidden as I began planning this thesis, half obscured in the undergrowth of a forest. It came to symbolise for me how this thesis has been a process of clearing away the undergrowth, metaphorically speaking, so that new "angles of vision" (Peshkin, 2001) might be revealed.

This task, which is one of meaning-making, was undertaken through a research method pioneered by Richardson (1994) known as "writing as a method of inquiry", and through what I have come to believe to be the refracting crucible of autoethnographic practice. In the end, the way this thesis unfolded has lead me into the complex arena of youth mental health, where so many of the perennial topics of youth studies meet up with matters of youth policy, research and practice, and with complex societal and institutional attitudes towards youth, especially mentally ill youth.

1.2.4 Intended audience

Many higher degree research students hope to reach a wider audience than their supervisory team and examiners. Since a specific aim of this thesis is to place a mother's voice in a scholarly and multidisciplinary context, my intended audience therefore includes parents, tertiary educators and teachers, those who work with young people in community services, as well as decision-makers and policy-makers.

This study is applied qualitative research, and applied interdisciplinary research fields are "especially *problem*-oriented rather than *discipline*-oriented" (Patton, 2002, p. 217, emphasis added). For this reason I deliberately positioned

myself within an education faculty where the interdisciplinary nature of youth studies finds a natural fit, rather than within an English department, even though I am primarily a poet by profession. This is compatible with my aim of talking across disciplinary borders. “We need to synthesize, not fragment, to talk across borders, not put up fences” (Fielding, 2017, p. 17).

1.3 Limitations

I am silent on some matters of my son’s life due to confidentiality or relational ethics considerations impressed upon me by ethics review and my own reading into autoethnography as a methodology. These are matters of “being silent”, however, rather than “being silenced”.

I have found it hard to confine my son within a single frame. “Musician, poet, social genius” says his headstone. He was also humourist, writer, skateboarder, iconoclast, avid reader, thinker, friend. Son.

Another limitation is that some topics, for instance the important issue of mental health literacy, could not be examined in more depth due to space constraints. I will return to limitations in this thesis in the Discussion chapter.

1.4 A guide to how this thesis is structured

While some of this thesis is presented in traditional chapter format with an “Introduction”, “Literature review” and “Methodology”, the reader will notice there are no chapters labelled “Findings” or “Analysis”. Instead there are two autoethnographic chapters, and these are the heart of the thesis.

The autoethnographic chapters (Chapter 4 and Chapter 5) do not follow a strictly chronological sequence, but a sequence intended for meaning-making, and could be read first, in isolation from the rest of the thesis, or after reading the two

framing chapters of “Literature review” and “Discussion”. In Chapter 4, the autoethnographic account of my experience of my son’s life might be regarded as the equivalent of a traditional thesis “results” chapter, while Chapter 5, where the autoethnography continues after my son’s death, could be regarded as the equivalent of an “analysis” chapter.

Within these autoethnographic chapters, I have used the technique of “layered” text (Ellis et al., 2011, p. 278; Lather, 1995, p. 53) in the limited sense of a text that shifts – for example, from time past to time present, from one kind of knowing to another as the evolving “self” of the autoethnographer moves from blindness to seeing. This is particularly true of the second autoethnographic chapter (Chapter 5).

The thesis concludes with a return to the mythical dimensions about the journey of youth. Of what story or stories do we find ourselves a part, at the end of this thesis? Was mine a chaos story or a quest, or was it a restitution story, the third of Frank’s typologies for stories (2010, p. 118)? In a chaos narrative, “one thing does not lead to another” – which is true of how the bright, energetic clever child we knew grew to be a quiet, reclusive young man suffering from depression whose depths few knew. In a quest narrative, there is a “movement towards meaning” and that is true of how our son strived to work out the difficulties in his life towards the end, “just living his life as best he could from day to day but according to his own principles and beliefs”, a life that was “a blessing to those around him” (private communication from a friend, 2007). My story however could also be a restitution narrative, but not in the sense of a healing of my son’s anxiety and his addiction – for there was his sudden death.

While his death marked the end of his life, just as it marks the end of Chapter 4, his death is not his story's "end-point" (Gergen & Gergen, 1988; Spector-Mersel, 2014). In the wake of my son's death, there continue to be reverberations and understandings, which lie along a spectrum of points of interpretation in Chapter 5, where the autoethnography continues in interpretive mode.

In many ways, this study has ended up being a restitution story, reassembling from the broken glass the window of meaning behind my story.

I have used italics to denote direct speech. Quotation marks can then more effectively denote the "citational approach" (Holman Jones, 2016, p. 234) which I have adopted to integrate research literature throughout the thesis, which serves to "enact the intervention of theory in the writing itself" (p. 234).

1.4.1 The structure of this thesis

1.4.1.1 Chapter 1 – Introduction

This thesis comprises seven chapters, including this, the first chapter.

1.4.1.2 Chapter 2 – Literature Review – An "ecology of knowing"

This chapter provides the scholarly basis for this highly reflexive thesis. The contested theories of youth studies as a discipline are explained in terms of the "twin tracks" of youth studies involving "youth transitions", an age- and stage-based view of "youth" as being on a journey towards the end goal of adulthood, and the more cultural view of young people as a "generation" (Woodman & Wyn, 2015). With uncertainty as a background to young lives, the "leitmotifs" of normality, giftedness, bullying and other "sensitising concepts" (Tracy, 2013) that spurred this research into action are explored in the relevant literature.

1.4.1.3 Chapter 3 – Methodology

Here I provide the theoretical and philosophic frameworks of the research and explain my methodology, autoethnography, which is an "ethnographic writing practice" (Holt, 2003, p. 2). I explain how "highly personalised accounts" can "extend understanding of a particular discipline or culture" (Holt, 2003, p. 2) and revisit my conceptual framework. Strategies taken to ensure rigor are outlined.

1.4.1.4 Chapter 4 – A chronology of knowing

This chapter consists of the autoethnographic study at the heart of the thesis. As the equivalent of a traditional thesis "results" chapter, it outlines how I came to know about what befell my son, the antecedents of the mental illness that often played havoc with his life, and eventually my knowledge about the true nature of his predicament. His death is not the end point of the narrative, which continues in the next chapter.

1.4.1.5 Chapter 5 – An anatomy of silence

This chapter continues the autoethnography, and serves the role of a traditional data analysis and interpretation chapter. With the intent of meaning-making the thesis moves now to broader themes. The gift of my son's life is that it bears examination, and becomes a way of portraying a different understanding of young people's battles with mental illness.

1.4.1.6 Chapter 6 – Discussion – An "ecology of understanding"

The study now moves from the personal to the public perspective, from the autoethnography and the wider world encasing it to reflection on the thesis's cultural aim. The chapter addresses many aspects of severe mental illness, such as models of psychiatric care, team approaches involving the family and close friends, the problems of finding effective services and treatment for youth suicidality and youth mental illness. Mental health policy, coordinated mental health care, community

action to support young people, youth mental health literacy, funding, and resources for parents and families are discussed, and avenues for future research are suggested.

1.4.1.7 References

Chapter 2

Literature review: "An ecology of knowing"

> Knowledge is frail, not fixed (G. Thomas, 2009, p. 69).

> … evidence is processual and hinges on what might be termed an 'evidentiary narrative,' which is reflexive of an ecology of knowing (Altheide, 2008, p. 140).

2.1 A view of the literature from the perspective of a reflexive self

As explained in Chapter 1, my positionality in this thesis is based on the reflexive use of three "selves": a *youth studies* self, a *mother* self, and my current self as researcher. The last of these evolves in the writing of this thesis, where my older self and my mother self merge, as a contemporary self, researching the field of youth studies and youth mental health from a personal or "lay" perspective. Using the three

perspectives of self, I hope to present a relevant "ecology of knowing" as a backdrop for the thesis. I co-opt these selves to answer – autoethnographically – my research question. Peshkin explores the use of positionality as one of many lenses or perspectives for undertaking research (2001, p. 242).

In writing this literature review, I tended to widen the lens to encompass a broader sweep of issues in the context of young people's lives, using the aerial view of things that hindsight affords me, for, speaking as my (contemporary) autoethnographic self, I am often uncomfortable with my past tense selves. Bradbury-Jones (2007) explains this reflexive use of the personal pronoun can make a text "multivoiced" (p. 292). These "angles of vision" (Peshkin, 1988) are important for autoethnography where we "*create* the self in the field (Y. S. Lincoln, Lynham, & Guba, 2011, p. 124, original emphasis). Autoethnography as a methodology and the literature that supports it will be explained in Chapter 3.

For an overview of this study's conceptual framework I will draw upon my "youth studies self" as my pre-thesis life was almost literally embedded in the literature of youth research in my "information manager" role at the Clearinghouse.

2.2 The time span of this literature review

A long time-frame is typical of many autoethnographic studies (Altheide & Johnson, 2011, p. 584). The autoethnography and this literature review will span three decades – from the mid-1980s to the present. This period includes my younger son's life (1984-2006) and the 10 years since his death. In that time I worked at the Clearinghouse (1995-2010) and began this study in 2014.

Within this time scale, another, very different, chronological map unfolds. The field of youth studies has emerged as a fully fledged field of inquiry in recent years, mature enough to have not only "a strong institutional and publication presence"

(McLeod, 2010, p. 249) but its own handbooks (for instance, those edited by Furlong, 2009; Wyn & Cahill, 2015) – compendium publications unimaginable when I was "in the field".

2.3 Youth studies as a conceptual framework for this study

I will first outline for the reader the contours of youth studies as a context for my research. In a broad-sweeping article on youth research written chiefly from a British perspective, Cohen (2000) points out that youth is a "strategic site of theoretical and methodological innovation", encompassing "the specific concerns of psychoanalysis and history, cultural geography and political economy, comparative sociology and cognitive psychology" – disciplines which "meet on [the] otherwise uncommon ground" of youth research. This makes questions about youth "central to debates about the social and human sciences" (p. 89).

For many years, two different theories of youth have represented a kind of "conceptual binary" that dominated youth studies. One involves a transitions metaphor of youth travelling or transitioning to adulthood (Woodman & Wyn, 2015, pp. 79-80). This is still embraced in policy settings where definitions of youth as age-based, stage-based people on a journey to adulthood and maturity gives rise to a structured view of youth.

The other ideologically very different "track" in youth studies is "youth cultural studies" where young people are defined by culture, and not in terms of time. The term *youth cultural studies* implies that youth are people first and foremost, within generations and within a social context. In youth cultural studies "youth" is a social construct, a social process, a generation (Woodman & Wyn, 2015, p. 108).

By contrast, youth transitions research, with its origins in psychology, conceives of a linear, chronological youth development that explains young people's transition to adulthood. This "transitions track" can be seen in a "life course framework" (Furlong, 2009, p. 4) but it also gives rise to the "deficit model" in youth studies, which sees youth as a period of risk requiring intervention (White & Wyn, 2008, p. 79). This gives rise to the "positive youth development" and "asset building" initiatives that aim to promote "successful" transitions and to build resilience in adulthood. See, for example, J. R. Olson and Goddard (2015).

Youth studies can be understood within a socio-cultural-political landscape as "youth sociology", encompassing the key ideas of "social change, the reproduction of social inequalities, cultural dynamics, generational relationships and the dynamics of the relationship between social structure and culture" (Furlong, 2011, p. 54). Seen through a cultural studies lens, youth research has a strong social justice ethos (Furlong, 2011, p. 54). Since the 1970s, the "central disciplines" in youth research have been cultural studies and critical theory (Mørch, 2003, p. 52) and youth research is often conducted from within the framework of critical qualitative inquiry. This is unsurprising, since critical qualitative research is concerned with issues of social justice and, in the educational sphere, in/equity (Pasque, Carducci, Kuntz, & Gildersleeve, 2012, p. 24)

My experience of youth research was grounded in both "youth transitions", and "youth cultural studies" at the Clearinghouse, which exemplified those twin tracks in youth studies even in its name, for originally, it had been called the National Clearinghouse for the Transition from School to Work, and rebranded as the Australian Clearinghouse for Youth Studies in 1998. It was an institution neutral in its

allegiances, striving to serve diverse youth research traditions and a very diverse audience ranging from academics to youth workers.

In theoretical contexts, the use of certain terminology, such as “adolescents” “young adults”, “emerging adulthood” immediately implies an allegiance to one or other particular youth studies perspective. For the purpose of this thesis, and acknowledging all the different strains and streams in youth research, I strive not to align myself with any one of them, using terms, such as “young adults”, in ways that are autoethnographically context-sensitive, unpinning them as I do so from their places on the chessboard of youth studies as a research field.

Much policy in Australia is framed around the concept of youth developing or transitioning “to a normative concept of adulthood” based on “the life course patterns of those born in the post-war baby boom”, where a “successful” transition to adulthood is seen to be “linear, involving set steps at prescribed times: through school, post-secondary education and into full-time work” (Woodman & Wyn, p. 272). The idea of seeing youth as a “time-based developmental process” appeals to many for its simplicity (Pollock, 2002).

While *youth transitions* research is age- and stage-related, and mostly policy-oriented, (Heath, Brooks, Cleaver, & Ireland, 2009), a *cultural* view of youth, focuses on issues of “belonging”, “agency” and “individual biographies” (Furlong, 2013).

In what could be called post-modernity, structural and societal change, uncertainty, insecurity and unpredictability make generalisations about the nature of youth studies complex. In North America, Côté (2000) speaks of transitions as “extended”, “arrested” or “on hold”, while in Europe, in research based on a project aptly named “Misleading trajectories”, Biggart and Walther (2006) speak of “reversible, fragmented and uncertain *yo-yo transitions*” (p. 44, emphasis added).

Researchers are "increasingly making a distinction between early and late youth and introducing new terms such as young adulthood or 'emerging adulthood' … to mark out what some regard as a new and distinct life phase" (Furlong, Woodman, & Wyn, 2011).

Some youth researchers have sought to find a middle ground between the "twin tracks". For example, Furlong et al. (2011) explore the changing relationship between the transitions and cultural perspectives as being driven by "shifting theoretical paradigms" placing greater weight on young people's individualised "reflexive life management" which makes it harder to maintain theoretical distinctions … between so-called structured pathways, and "cultural analysis" (p. 355).

The relationship between the twin tracks is showing signs of convergence as other contested issues arise in youth studies, such as "youth agency" (Coffey & Farrugia, 2014). I will return to youth agency later in this chapter.

As the formerly clear distinctions between the "twin tracks" of youth studies – youth as culture and youth as transition –dissolve, merge, or become "unsustainable" in a research sense (Woodman & Bennett, 2015, p. 186), debate between adherents of each of the "twin tracks" continues in the realms of contemporary youth research (Furlong et al., 2011, p. 359). These issues have implications for how, as Coffey and Farrugia put it, young people's "biographies, identities and decisions are shaped by, and contribute to, the on-going production of their social environments" (2014, p. 472) – and it is the social environment that often plays an important if sometimes invisible role in the autoethnographic chapters that will follow.

Where youth studies is of particular relevance to my study is the way the multifaceted and colourful contours of youth studies as a discipline have extended out

into disciplines beyond the socio-political realm, such as health, mental health, psychology and clinical medicine, since it was into these areas that my own and my son's life were inexorably drawn. However, in these disciplines, the new thinking in youth studies beyond the strictly "transitions" track is not apparent. The idea of youth transitions persists in many policy settings although it is an idea derived from the previous century when such transitions were stable and predictable. However, in contemporary times, youth transitions have become increasingly irregular and unpredictable, if not chaotic, and using the youth transitions model of research to understand the rich diversity of young people's lives has become problematic. "Youth no longer inhabit the privileged space, however compromised, that was offered to previous generations" (Giroux, 2014, p. 37).

While assumptions about transitions might be challenged and debated *within* the field of youth studies (te Riele, 2004), out in the wild, the transitions model persists.

In the policy sphere it is common to find the transition model's age-and stage-based foundation at work in anything relating to youth, seemingly as a normative practice. This is because the "transitions" and the "cultural" approaches involve differing theoretical and methodological frameworks. A cultural approach in youth studies tends to draw on "ethnographic and small-scale research of young people" while research from a transitions perspective "particularly [by] those interested in the relationship between education and work, [has] tended to favour large-scale quantitative studies and … longitudinal research" (Furlong et al., 2011, p. 356). The result, as these authors point out, is that the literature of youth studies presents differing insights about young people's lives, and this in turn has had practical outcomes in many service settings. The outcomes also play out in *personal* settings: I

realise in retrospect that it was as if my tacit knowledge was partly based in the story of youth transitions while the broader story of my life with my son played out in the story of youth cultural studies: two somewhat opposing endeavours.

This distinction in methodological approaches to youth studies in the "meta" sphere plays out at the physical level: it has implications for how we divide hospital wards by age, so that child and adolescent mental health wards are for people aged 0 to 18, and adult psychiatry wards are for those aged over 18. However some recent, innovative child and adolescent medical services treat the youth cohort as a distinct group with their own, very particular needs that are very different from both child mental health and adult psychiatry. Of interest to this study is the "deterioration in [youth] mental health during the post-secondary education years" which, coupled with the pressures young people experience, contributes to "the idea that such 'storm and stress' are not a 'transitional' experience" (Woodman & Wyn, 2015, p. 80). The leitmotif of "sturm und drang" pervades this thesis.

2.4 Threshold concepts for this research

While threshold concepts (Land, Meyer, & Flanagan, 2016) can help explain a field such as youth studies, they are also a source of "troublesome knowledge".

As early as 1998, Johanna Wyn and Rob White were arguing for a view of youth as a "social process", for research on young people that did not compartmentalise their lives into discrete ages – or problematise "youth issues" to the detriment of more holistic accounts (Wyn & White, 1998). New metaphors for discussing young people's lives have arisen, for example the idea of a "sociology of generations" (Andres & Wyn, 2010; Woodman & Wyn, 2012). Wyn's focus on youth as generation moves the emphasis away from the idea of "linear development in which youth is a phase towards adulthood" and instead places young people's lives

"within the political, economic and cultural processes" (Wyn & Woodman, 2006). However it is not always an either/or situation: transitions are examined rigorously in Cuervo and Wyn's (2011) report, *Rethinking youth transitions in Australia: A historical and multidimensional approach,* where a comprehensive view of the varieties of youth transitions in contemporary Australian lives is based on over two decades of data gleaned from the Life Patterns Project, a longitudinal, mixed methods panel study that began in 1991 at the Youth Research Centre at the University of Melbourne.

A strong theme in Wyn's work is the argument for bringing the family back into youth studies (Wyn, Lantz, & Harris, 2012). Biggart and Walther (2006) highlight the supportive role families play in the "close interrelationship between individuals, families and the state" (p. 59). This interrelatedness is often neglected or minimised as simply an economic or cultural stereotype, where "family" is code for "traditional social structures". Sometimes family is seen primarily as "an obstacle for young people's biographic construction" (Biggart & Walther, 2006, p. 59). By contrast, more recent research – for example in the annual surveys of youth opinion conducted by Mission Australia (V. Bailey et al., 2016) – shows that youth place family very high on their list of what is important to them. In earlier surveys the idea of "belonging" had emerged as important for young people and thus became a "relational metaphor" in Australian research for theorising about young people's lives (Cuervo & Wyn, 2014).

There is something strange about changing gear from the close-up view of youth in the youth studies world where family and belonging have been highlighted, and travelling to the policy realm, where, it would seem, youth are all but invisible. In contemporary Australian youth affairs, the former distinct youth affairs cabinet

portfolio has disappeared. As a ministerial responsibility youth as an area of concern has melted away from view and has been blended into separate government departments. This is relevant to this thesis as it makes it hard for community voices, such as mine, to find the appropriate "place" in which to voice concerns that are not specific to "education" or "housing" or "welfare". The silo'd nature of government will be discussed in Chapter 6. My point here is, so much about young people's lives is multidimensional, intertwined.

Uncertainty for youth escalated to new levels in Australia in 2014 with threats by government to curtail expenditure on youth-related programs and welfare policies. Many youth affairs institutions and peak bodies, steadily built up over the past 20 years by successive governments, were defunded – along with the 35-year-old Clearinghouse where I had worked. From a policy perspective, young people are arguably in a more precarious position now than ever before in Australia.

Writing of a similar state of affairs in the USA, Giroux (2014) points out that most youth tend to blame themselves and not society or its systems that have structured them out of the mainstream picture and that have blocked or put on hold their future prospects. Giroux writes that today's youth, unlike previous generations, are "no longer the place where society reveals its dreams. Instead, youth are becoming the site of society's nightmares", defined by the "contradictory symbols" of "consumer", "a drain on the economy" or "intransigent menace". This, for Giroux, forces many young people to "negotiate their fates alone, bearing full responsibility for a society that forces them to bear the weight of problems that are not of their own making and for which they bear no personal blame". With a characteristic flourish, Giroux then inverts Mills' famous dictum by saying that public problems have now

collapsed into "the limited and depoliticised register of private issues" (Giroux, 2014; Mills, 1959).

With increasing uncertainty in their lives, complex issues of a more abstract and intangible nature are coming into the frame in recent research, relating for example to belief and meaning in young people's lives.

2.4.1 Understanding young people's existential angst

Italian researcher Carmen Leccardi (2005), writing from a "youth transitions" perspective, finds that while most young people are "actively coping" with the "new uncertainty" of the 21st century, "many … seem today to be suffering from [a] kind of widespread angst". That angst is, for Leccardi, born from a "pervasive feeling" that while everything seems to be going faster, youth transitions are "almost snail-paced" producing an "insoluble contradiction" that generates a "feeling of 'belatedness' in regard to steps that … have lost their link to … temporal milestones" such as ending educational studies, starting work, or creating an independent family.

The idea of youth being a period that is angst-ridden is not new or unique to our era. Goethe's first and most successful work during his lifetime, *Sorrows of young Werther*, is arguably the first novel about youth suicide in modern times. Published at the height of the romantic era in 1774, it is an example of existential angst carried to an extreme. It portrays its hero and his fate in what seems to be an almost callous, matter of fact manner so different to the clinical perspectives in contemporary research literature.

At times, adolescent angst has been regarded simply as a "normal" phase for young people to experience and pass through as they mature, an idea found in the work of Polish psychologist and psychiatrist K. Dabrowski. His "Theory of Positive Disintegration" was never fully completed in his lifetime. It views the chaos and angst

in young people's lives as not pathological but as a "normal" part of maturing to a state of stability, where the ability to weather crises is achieved. It is hard to imagine Dabrowski's theory standing up against the waves of pressure on young lives imposed by drug-induced psychosis, but his non-stigmatising, non-pathologising view of young people interests me: he asserts in the title of one of his books that *Psychoneurosis is not an illness* (Dabrowski, 1972). Much of his research was focused on gifted young people and on excitability as a defining characteristic of the gifted. My son was definitely overexcitable (C. L. Bailey, 2010), and prone to existential angst. This spurred me to question how we can know what is "normal" in adolescent angst?

The concepts of existential angst and a search for meaning became companion concepts as I explored existential angst in young people, which seems to be an understudied area of research. Hacker's (1994) paper, "An existential view of adolescence" explores the development of abstract thought in adolescence, linking it to existential issues. He believes adolescents can be acutely aware of feelings such as the dread of death, the confusion of indecision, the hopelessness of meaninglessness, and the despair of isolation (p. 308). He calls for more research on how abstract thought develops, and on the ways adolescents "understand their personal worlds and what is of significance in those worlds" (p. 304). Drawing on Western philosophy and psychology, Hacker believes that adolescent existential angst is a response to an experience of meaninglessness and alienation (p. 316).

Sensing my own son's existential angst, I gave him Viktor Frankl's *Man's search for meaning* to read in his last year. It is important for young people to understand their own personal isolation, loneliness, belonging and becoming as they find their place in the world – "many adolescents are so alienated from peers, family,

or society that a search for meaning becomes impossible" (Hacker, 1994, pp. 304,316).

Young adults who experience existential crises would seem to be suffering silently on a scale of difficulty that we do not know about, with an existential angst driven by both their own inner, private and psychological turmoil, as well as external, environmental pressures beyond their control. The connections between young people's mental health and their existential fears about the future and the environment are discussed by Eckersley, Cahill, Wierenga, and Wyn (2007); Gordon and Lahelma (2002); Lamont (2012); and Lindfors, Solantaus, and Rimpelä (2012).

Several researchers have brought to light evidence that gifted learners are particularly prone to existential angst (C. L. Bailey; Bratter, 2007; Eckersley et al., 2007; Ellsworth, 1999; Fitzgerald, 2005; Hacker, 1994; Lindfors et al., 2012). An overview of research that links gifted learners with a heightened tendency to experiencing fear and existential dread is provided by Lamont (2012) – along with practical ideas for parents to address the existential fears of their children. I first became aware of a possible link between gifted learners and existential angst through reading a small paper which claimed that "existential dread poses a threat to adolescents' self-esteem, productivity, and life itself", which concluded that adults can, through a team approach, "reduce the amount of time youth languish in the throes of existential dread and lessen the threat of depression and suicide" (Ellsworth, 1999, p. 408).

Research on young people in China suggests illicit drugs are used to relieve the anxiety that arises from these "existential issues at this life stage" and "searching for the meaning of life" (To, Sek-yum Ngai, Ngai, & Cheung, 2007, p. 327). The idea of a quest for meaning brings the threshold concept of hope into focus.

2.4.2 Hope

With regard to hope, Australian research has highlighted the important role of hope in determining the trajectories of young people's lives (Bishop & Willis, 2014; Eckersley et al., 2007; te Riele, 2010). Its counterpoint, hopelessness, is discussed in terms of young people's existential attitudes, for example in research by Brassai (2012) – within the context of behaviour regarding health. Sometimes, the sense of hopelessness that young people with psychosis experience regarding their future can be shared by the mental health professionals who care for them (T. Lincoln & Beck, 2014) – a disempowering feeling which can be averted through specialised early intervention programs that offer individuals with psychotic disorders as well as their families "new hope for improving illness trajectories" (Cotton et al., 2016).

As a field of endeavour, youth research is "well positioned to play a lead role in exploring the links between people's hopes and fears, their concerns of everyday life and the big picture questions about the future" hopefully creating "new spaces for dialogue between generations" (Wierenga, 2011), and importantly, I would add, between disciplines.

In school contexts, Larsen's (2007) research on narrative counselling with adolescents revealed that hope was " an implicit aspect" of the adolescent self, an unexpected finding for the author, who then posited the idea of an adolescent "hoping self" that is "pervasive" during adolescent development (p. 255).

2.4.3 The promises and problems of academic giftedness

Giftedness, in particular academic giftedness, served as a threshold concept (Land et al., 2016) for framing both my research question and aspects of the autoethnography that follows. Giftedness can come in a variety of colours. Gardner lists at least seven in his theory of "multiple intelligences": linguistic, musical,

logical-mathematical, spatial, bodily-kinaesthetic, interpersonal, and intrapersonal (1993a, 1993b). Giftedness poses difficulties for parents regarding the identification of one's child as gifted (Carman, 2013; Gallagher, 2015a, 2015b). A parent can be perceived to be pressuring their child to over-perform. Another difficulty is the "dearth of research on the experience of parenting gifted children" and "few studies have been conducted on parents of the gifted … especially in relation to children's behavioral and emotional issues" (Renati, Bonfiglio, & Pfeiffer, 2016, p. 3).

Australia has its own way of treating those who stand out from the crowd in a characteristically cheerful and offhand fashion. When emigrating to Australia we had been warned about the "tall poppy syndrome", explained by Riley (2000). A pejorative way of looking at giftedness is through the "mad genius" theory of intellectually and creative giftedness, often advanced without anything to support it.

Problems with how academically gifted children are treated – as tall poppies, as mad professors – are not unique to Australia. Coleman et al. (2015) have analysed 25 years of qualitative research accounts of gifted young people's battles with "identity, passion, labelling, stigma, culture, schooling, academic resistance, and bullying" (p. 358).

2.4.4 Bullying, resilience and the problems of agency

My interest in my two sons' giftedness became subsumed by concerns over school bullying. Not long after I had bought Gross's (1993) book, *Exceptionally gifted children,* I found I was exploring *The optimistic child* (Seligman, Reivich, Jaycox, & Gillham, 1995) instead, and trying to work out our younger son's huge propensity for pessimism and negativity. It was at this time that information on school bullying had begun to burgeon. Resilience literature also came to the fore, with books

by Australian educators Andrew Fuller, Stephen Biddulph and Michael Carr-Greg becoming popular with parents.

Research on bullying in the transition period between primary and secondary school by Lester and Cross (2014) provides one key among many to my son's story: "Males who experienced low, but increasing, levels of victimisation over secondary school had greater emotional symptoms, conduct problems, hyperactivity, peer problems and lower pro-social behaviour than those who had not been victimized" (p. 137). Victimisation has been found to be linked with the development of depression later in life (Bowes, Joinson, Wolke, & Lewis, 2016, p. 181).

The meaning of youth agency is often debated in youth studies, where its meaning varies with the contexts that deploy it. Agency is explored by Coffey and Farrugia (2014) as typically referring to "active subjectivity, intentional action or 'free will'". This is of personal interest to me as my younger son was obsessed by determinism and issues of free will. As a "consumer" of mental health services, agency became a hugely important issue in his life. Coffey points back in time to earlier researchers who outline how agency lies behind the choices or decision-making and forms of self-expression of youth (Wyn & White, 1998). Here, agency is seen in relation to the societal "structural constraints" beyond the young person's world – structures which are "either irrelevant or invisible" if we focus on the individualistic nature of the choices made by young people. Coffey et al. move the debate about "the problem" of agency to one of "youth subjectivities and social action" (p. 461).

2.5 Youth mental health

I emphasise that throughout this thesis, I am approaching issues relating to mental health not from a medical perspective, but as a member of the community, and

as an advocate with an education and social science perspective. It is worth noting that experts in the field of mental health are themselves often also advocates for improvement in mental health. However, when prominent scholars entreat parents and "the community" to voice the need for policy attention to youth mental health, their words seem to me to hang in the air uncertain of where exactly they should land. The thorny ground of youth policy is surrounded by stony silent spaces across which the community voice needs to shout.

It takes a village to raise a child …

The absence of the mother's voice in the arena of youth mental health might be due to the overwhelming nature of the experience of mental illness in families, and the confronting nature of undertaking research into that experience when it ends with the death of their child, as it did in my case. I never reached the stage of identifying with the term "carer" as described by Wynaden (2007) where, overwhelmed by the situation in which they find themselves, one moves from a state of chaos to a state of order. Writing 10 years after my son's death and reading Wynaden, I imagine "carer" as a person dressed neatly who is managing life in a reasonable, thoroughly calm manner, perhaps with the aura of a halo about their head, acting in an ordained role. I was simply "mother" doing what mothers do – caring, yes, but also multitasking as wife, mother and parent of a sibling-who-is-not-mentally-ill, friend and neighbour, employee…

Added to this, a parent must also be an advocate for their child's health interests, and yet while so doing, might also find themselves progressively excluded from decision-making:

> After learning to become advocates to secure appropriate services for their children, in late adolescence and young adulthood, parents are

likely to find themselves excluded from their children's treatment planning and services. (Jivanjee, Kruzich, & Gordon, 2009, p. 435).

Bridging the worlds of youth studies and youth mental health, Jivanjee et al.'s article, "The age of uncertainty: Parent perspectives on the transitions of young people with mental health difficulties to adulthood", echoes the major through-lines in this chapter discussed up to this point, and adds the crucial theme of finding supportive networks, though here, the networks are for the parents; we will reach the crucial issue of networks for youth later. Written from within the transitions tradition of youth research, Jivanjee et al. present parents' experiences of their mentally ill children's lives, and families' struggles with "anxiety, uncertainty, and other painful emotions" (2009, p. 444), underscoring the invaluable role of the family in the lives of youth. The article is like an action-plan for parents, recommending for example, that parents do "transition planning" for their child's future (p. 443). Had I read this study during my son's lifetime, it might have helped me find ways to mitigate the kinds of problems that arose in our own family when, for example our son was old enough to manage his own affairs, and when laws to protect his privacy effectively locked us out of not only the many decisions surrounding treatment but even the knowledge that any treatment was underway. Australia's privacy laws exist to protect people, yet that defensive shield can itself be a barrier if it means that a care-giver is deprived of knowledge relevant to their loved one's condition. Jivanjee et al. (2009) discuss this problem faced by parents as chief care-givers, where confidentiality makes it "hard for parents to get the information they [need] to help their children" (2009, p. 443), especially adult children.

2.5.1 Youth mental health policy

Youth mental health policy in this thesis is viewed against the background of Australia's mental health system, which has "fundamental structural shortcomings" – a conclusion that has been reached "by numerous other independent and governmental reviews" (Hickie, 2015, p. 3). I found many papers over the past decades revealed a variety of problems in implementing youth mental health policy in Australia (Australian Senate, 2006; Commonwealth of Australia, 2015; Freijser & Brooks, 2013; Hickie et al., 2014; Newman, O'Reilly, Lee, & Kennedy, 2015; Rosenberg & Hickie, 2013; Rosenberg et al., 2015; Welsh et al., 2015).

In a significant review of the priorities for policy to promote youth mental health in Australia, Rickwood (2011) shows that Australia has been at the forefront of many youth mental health promotion initiatives, particularly in regard to "service reorientation" and "personal skills platforms" listed in what is known as the Ottawa Charter (p. 40). That charter is accepted as the "definitive framework for health promotion ... and specifically for mental health promotion", and is valued for the way it "ensures a wide-lens view of mental health promotion that spans the individual to the societal. It incorporates the personal, political, societal and clinical, arguing for personal agency, public health, health system and ecosystem perspectives – all of which underpin a holistic and interactive whole person–whole community approach" (p. 41).

In Rickwood's assessment of critical needs in Australian contexts, she cites, among other needs, the need for policy focus in terms of "oversight of all public policies for their impact on youth mental health – and the need for "more supportive environments for youth and better interconnection with mental health care". Importantly she cites the need for community action "to support the youth voice" as well as the need for "investment in resources for parents and families" (p. 40).

Within the literature on mental illness in young people, a narrow band of research relating to youth and psychosis is relevant to this thesis. Issues at stake here are the care they receive in psychiatric intensive care and psychology wards in hospitals, the matter of agency or a "locus of control" in these young people's lives, and the issue of support systems and networks for them on their discharge from medical settings.

Youth agency, mentioned earlier, is a complex matter for all young people but especially for those who are mentally unwell and involuntarily confined to psychiatric wards. Papers such as "The locked psychiatric ward: Hotel or detention camp for people with dual diagnosis" (Terkelsen & Larsen, 2013) are of interest regarding comorbidities where a young person suffers from two different conditions requiring differing treatment approaches. Those suffering from both mental illness and substance abuse are "more difficult to manage than any other group of mentally ill clients". Programs that focus on both illnesses in a dual diagnosis achieve better outcomes (Kenny et al., 2006), but in my experience such programs were impossible to find for my son.

The move to provide care and treatment for the mentally ill within the community has been underway in Australia for several decades. One consequence is that mentally ill youth are more exposed to illicit drugs – socially isolated clients are more easily drawn into a drug-using culture, due to its less stigmatising responses towards the mentally ill, or perhaps they drift that way "simply as a result of boredom, difficulties coping with everyday interactions, or a lack of meaningful activity in their day" (Kenny et al., 2006, p. 13).

2.5.2 The shame and stigma associated with psychological suffering

The trajectory of this thesis has drawn me deeper into an exploration of shame and stigma than I had expected. The need to improve the often stigmatising attitudes of society towards those with mental illness is a theme common to several studies I examined. Jones and Crossley (2008) define stigma as the outward sign of the inner feeling of shame (p. 750), an emotion that lies at the core of much psychological suffering, including bullying for example. Descriptions of young people's experiences with stigma, and ways of mitigating their effects, abound (Boyd et al., 2007; Clement et al., 2015; Corrigan & Miller, 2009; Elkington et al., 2012; Elkington et al., 2013; Hinshaw, 2005; Large, Ryan, Walsh, Stein-Parbury, & Patfield, 2014; Livingston, Milne, Fang, & Amari, 2012; Mason, Hart, Rosetto, & Jorm, 2015; O'Driscoll, Heary, Hennessy, & McKeague, 2015; Pescosolido, Martin, Lang, & Olafsdottir, 2008; Robinson, Bailey, Browne, Cox, & Hooper, 2016).

In a systematic review of interventions for reducing stigma related to substance use disorders, Livingston et al. (2012) found "limited evidence" that "therapeutic interventions" helped to reduce stigma. Instead they found that interventions that were focused on reducing stigmatising *public* attitudes, through "motivational interviewing and communicating positive stories of people with substance use disorders", were most effective (p. 45). For example at the structural level, programs to educate medical students about substance use problems and which exposed them to people with substance use disorders were likely to decrease these students' stigmatising attitudes and to increase their "comfort levels" when working with this population (p. 47).

Shame is commonly experienced in young people admitted to psychiatric wards, as shown in many studies. In hospital my son was stoically silent but I saw

him cry there. It was heartbreaking and I was at a loss to help him. This underlined for me how the patient's feelings of shame often go unvoiced.

> Patients often find the admission process humiliating and fear that psychiatric hospitalisation will be stigmatising. Inpatients, both voluntary and involuntary, often believe themselves to have been coerced into hospital. Patients treated in locked wards sometimes describe 'being trapped in a situation where they had to endure being controlled'. Psychiatric units can be frightening places, where verbal aggression and violence may be observed or personally experienced. The experience of being hospitalised can be frightening, demoralising and demeaning or induce feelings of abandonment, oppression and heightened vulnerability. (Large et al., 2014, p. 119).

The "shame, loss of adulthood and a sense of personal failure that result[s] from being admitted to an inpatient setting" is well understood by professionals, but Newman (2015) believes it needs reiterating in order to persuade non-professionals – in hospitals – and service providers to better meet their patients' needs. This shame will reveal its sometimes traumatic nature later in this thesis. Newman's integrative review of the literature on mental health service users' experiences of mental health care identifies stigma as a significant barrier for service-users accessing help, and his study, like others already discussed, underlines the significant shame felt by patients on admission to psychiatric care in hospital.

Newman reviewed mostly British models of care, and uncovered many unsettling issues. These included patients' experience of fear and coercion in hospital, "poor continuity of care and care planning … throughout the mental health service" (p. 21), a lack of involvement in treatment choices for people with mental health

problems, fragmented systems, and deficits in the "relationship aspects of care" that require further investigation (p. 23).

2.5.3 Mentally ill youth and help-seeking

Help-seeking is problematic when it comes to serious mental illness in young people. For example, a growing body of evidence suggests only a minority of young people who experience suicidal thoughts or self-harm seek professional help. Worryingly, this includes seeking medical help after an overdose (Michelmore & Hindley, 2012, p. 507).

The help-seeking of youth with suicidal ideation is discussed in a recent national report from Orygen Youth Health at the University of Melbourne. It reveals that youth suicide in Australia reached a 10-year high in 2016, outlines the need to "equip family and close friends with the skills to identify risk and lead helpful conversations", and reports that among all young people experiencing suicidal thoughts or behaviours, "help-seeking rates are low particularly with regard to young men" (Robinson et al., 2016, p. 16). Once again, stigma is cited as a barrier to seeking support, along with "fear" and "embarrassment". Other common barriers to help-seeking were the fear of being forced to talk about personal problems, concerns about confidentiality – and specifically, the fear of being admitted into hospital. More practical barriers included access to services, time, and personal resources (Michelmore & Hindley, 2012; 2016).

Young people do seek help from their social network of peers (Michelmore & Hindley, 2012, p. 507). This underscores Rickwood's (2011) supportive call for more investment in resources to support families, since much research on young people and help-seeking has shown that it is to families and to peers that young people experiencing mental health problems will turn (Hom, Stanley, & Joiner, 2015;

Robinson et al., 2016; Smith, 2012; Wahlin & Deane, 2012; Wilson, Cruickshank, & Lea, 2012).

The important role families play in regard to youth mental health is a theme in many reports. “When young people do seek help they often turn to informal sources of support such as their parents and peers as opposed to professionals, according to both Ivancic et al. (2014) and Robinson et al. (2016). However, the efficacy of family as sources of help is highlighted as problematic in some of the grey literature. For instance, a 2016 survey by Yourtown (2016) showed that sometimes, young people found parents not as helpful as they could be (Robinson et al., 2016, citing a 2016 Yourtown report).

Michelmore and Hindley (2012) found few studies had focused on the nature of help received from peers, and those available revealed that fewer than a quarter of young people who had supported a suicidal peer ever told an adult about the matter or suggested seeking adult help. Echoing Rickwood’s (2011) research, the 2016 Orygen report on youth suicide cited above (by Robinson et al.) recommends that youth suicide prevention activities need to focus more on the role of family members and peers in regard to “the delivery of resources, supports and training so that they can better identify, respond and refer” their child/sibling/friend. Robinson et al. found that friends and family often cited the lack of being equipped with “the tools and resources to respond effectively to such a confronting and complex experience in someone they care about” (p. 18). Such lack of provision is yet a further barrier to mentally ill youth getting the help they need.

2.5.4 Mental health literacy

To help his younger brother, my elder son, of his own initiative, enrolled in the very first roll-out of the youth mental health first aid course in our state. The

training that he received helped support François when he was mentally ill and in times of acute crisis. Crucially, this training helped identify that a crisis was an acute one in the first place. Thanks to my elder son's training we were able to rush François to hospital and save his life on several occasions.

The need for mental health literacy is strongly featured in the literature on youth mental health, regardless of its context (Gagnon, Gelinas, & Friesen, 2015; Hom et al., 2015; Kelly, Jorm, & Wright, 2007). Some of the literature is aimed somewhat narrowly at professionals who work with youth (Ranahan, 2010), but more recent literature points to the need for family and friends to know how to support a mentally ill person, not only in a crisis, but in general (Hart, Mason, Kelly, Cvetkovski, & Jorm, 2016; Jorm, Kitchener, Kanowski, & Kelly, 2007; Kelly et al., 2011; Ross, Hart, Jorm, Kelly, & Kitchener, 2012; Yap & Jorm, 2012; Yap, Reavley, & Jorm, 2012).

2.5.5 The importance of meaningful work to youth experiencing mental health difficulties

There is much literature on the salvation that working achieves for those with mental health problems, from Estroff's (1995) "Brokenhearted lifetimes" to the recent report, "Tell them they're dreaming: Work, education and young people with mental health in Australia" (Orygen Youth Health Research Centre, 2014). Some research describes the beneficial effect of work on levels of mental illness experienced (Buchholz, Aylward, McKenzie, & Corrigan, 2015; Issakainen, 2014).

François had tried hard to earn his own way. It was hard to connect him with employment and I often paid him from my own pocket to work on my small press, editing books, web pages and other documents, a task he did with stunning accuracy. He enrolled in an editing course, and in an accounting course at the height of his illness. To keep his welfare benefits he was duty-bound to go to employment agencies

to seek work. I drove him to one such appointment in a fluster as we were late. He went into the interview despairingly, but came out with a wry smile – and a job with the welfare agency itself. It was a short-term contract, but he worked hard and never missed a shift, no matter how ill he felt. He was devastated when this work did not continue. *I have lost my job,* he would tell people.

Do gifted children who do not live out their "promise" experience a huge sense of failure, and what are the consequences of that feeling? How can parents avoid that trap, and how do you on the one hand, encourage them to find work in which they can flourish and on the other, entertain no – zero – expectations? How to get them to see that finding work is a problematic, even a structural issue in society, and not always within young people's personal control, as Giroux (2014) explains?

2.6 The importance of networks for supporting young people

A unifying theme in this thesis, as well as the literature on difficult issues regarding youth, is the idea of using teams, networks, groups of people working together in order to find solutions for young people and especially for youth in crisis. Ellsworth (1999) and a decade later, Jivanjee et al. (2009) express the need for support networks and a team approach, although Ellsworth does not elucidate how that network might be formed. In the realm of gifted education Csermely (2017) has applied his knowledge of network science to explore how social networks can support talented people. With regard to mental illness, Macdonald, Hayes, and Baglioni (2000) compared the social networks and perceived social support of 26 people with early psychosis and 26 people without a mental illness, finding an "important relationship between strong social networks and high levels of community functioning" (p. 25).

The benefits of a team approach to solving youth mental health issues has been explored by several researchers (Hartman & De Courcey, 2015; L. Hoffman, 2007; Seikkula & Olson, 2003). A "new bright edge" of dialogic therapies is described by L. Hoffman (2007) in an important article that introduces us to "dialogic therapies" grounded in the ideas of Bakhtin, Wittgenstein, Gregory Bateson, and others. She explains Norwegian psychiatrist Tom Andersen's "Northern Network", composed of teams handling acute breakdowns from hospitals in countries all across Europe's northern rim" which uses the concept of the "reflecting team" and Andersen's idea of "withness practices". These ideas are taken up by "innovators such as Jaakko Seikkula … [in] an approach called "Open Dialogue" (L. Hoffman, 2007, pp. 63,64,67).

Mary Olson's background in dialogic network therapy lead her to work with Seikkula and the "Open Dialogue" model of early intervention for psychosis. This thesis makes frequent reference to Open Dialogue", a team-of-teams approach linking experts, parents, doctors, peers, and the patient in regular team meetings with everyone on a level playing field. "Open dialogue is of particular interest to Australia which has invested heavily in specialist early intervention in psychosis, the cost effectiveness of which is [sometimes] questioned" (Lakeman, 2014a). An example of Open Dialogue's application in Australia is provided by Hartman and De Courcey (2015).

2.7 Audience and paradigmatic differences in youth research

Much research on youth is written from a health perspective, and especially in the clinical, psychological and mental health fields, is written from the perspective of the evidence-based practice movement. This is significant for my study, which takes

an applied qualitative research approach. At a pragmatic level, the distinction drawn by Altheide and Johnson (2011) below explains why I often felt I was wading through material intended for experts in the hopes of finding material relevant to people on the ground like parents, teachers, and service providers. I cite Altheide and Johnson at length to avoid blurring the point they make:

> While many anthropologists or sociologists who practice qualitative research might be primarily motivated to make fundamental contributions to the *basic knowledge* of their disciplines, or contributions to a *substantive problem area,* those who practice qualitative methods in clinical studies typically intend a different audience, [namely] those interested in advancing *effective clinical practice* (pp. 582-583, emphasis added).

Altheide and Johnson then draw attention to how the criteria of usefulness is linked to the purpose behind the research, and in that regard I would like to emphasise that this thesis is written with the intention of helping to shine a light on "a substantive problem area*"*. If I seem to be critiquing "effective clinical practice", this has more to do with how the perspective of a mother is absent from much evidence-based practice narratives than it has to do with any presumption on my part.

2.8 On *not* reading the literature

In closing this literature review, I would like to disclose one important "autoethnographic fact" about my reading of the literature. During the dis-ordered life trajectory that I describe in the next two chapters, I could not read. Or rather, I could not *absorb* what I read, in the heat of the moment as we travelled from crisis to crisis in the last years of my younger son's life. It was a journey I travelled largely without

reading. Yet I was a librarian. For me, this state-of-not-reading endured in my life from the crises of the last few years of my son's life, through grief and onwards until the commencement of my thesis work.

It is beyond the scope of this thesis to investigate how common it might be for parents in crisis to experience this kind of incapacity for absorbing written information. However, this state throws into stark relief the few resources I *did* manage to read at the height of my younger son's troubles. One was the March 2006 issue of *Youth Studies Australia,* which came out shortly before my son's death. It focused on youth mental health and mentioned the first iteration of the COOL TEENS anxiety management program for youth, now widely propagated. It helped me understand the seriousness of my son's distress. Another was a passage in *Living with fear* (Marks, 2001) that helped our family to understand obsessive compulsive disorder. The book's back cover informs the reader that OCD sufferers who used this book "improved as much as sufferers guided by a psychiatrist". Importantly, a psychiatrist treating my son had placed the book in my hands. I doubt that there is much else that might have been helpfully placed in our hands to read when we were all sleep-deprived and in extreme stress. We lived in coping mode. However, this literature review is not about the resources that *might* have helped at the time. Rather, it is about the wider contextualising literature that "explains" and substantiates this particular kind of applied research which might easily fly off the page were it not grounded in the scholarly literature.

An extremely useful, though not strictly academic, resource I read at the time of our son's hospitalisation was a set of short, insightful, well-researched pamphlets from the not-for-profit organisation, SANE Australia. I read these – again, at the recommendation of a psychiatrist – at the height of a crisis, during my son's hospital

admissions. What I recall is not so much the words but a cover image of one publication with two empty chairs facing each other. Recently I noted the cover of *The SANE guide to psychosis* is a sketch of three empty chairs with their *backs* to each other. However, both the image in memory and the image on the actual cover represent to me the need for a dialogical dimension in the lives of the mentally ill and in our ways of working with the mentally ill. This dialogical need will become a recurring theme in this thesis.

At the time of my son's crises, while *reading* new information was hard at times, *writing* has always been an essential and integral part of my life. A practice of regular writing was critical both to my scholarly methodological process as it had been to the grieving process. This writing provided the "inscape", to use Gerard Manly Hopkins' term, for the emotional landscape behind this thesis – a territory I explored by writing a book of poetry, in tandem with, but separate from, this thesis (*The White room poems*).

The theoretical and philosophic frameworks behind this thesis will now be discussed, in Chapter 3, *Methodology*.

Chapter 3

Methodology

Chapter 2 described the youth (cultural) studies framework and the main themes in the literature behind this applied qualitative study. I now set out the philosophic and theoretical frameworks of this research, which is positioned within the interpretive paradigm. I then discuss the methodology and approach I have used – autoethnography – and how this suits the philosophic and theoretical underpinning of this study. I explain how a "critical" theoretical lens helps address my research question, and outline strategies taken to ensure rigor. Finally I describe how I have strived to meet ethical expectations in my research.

3.1 Philosophic and theoretical frameworks

I have chosen a qualitative approach to my research because both my research question and the topics I explore are multi-faceted and complex, and focus on data that are personal, emotional and particular. The philosophic framework underpinning that choice now needs clarification.

Research paradigms, as the "overarching philosophical systems that denote particular ontologies, epistemologies, and methodologies" (Clough, 2000; Denzin & Lincoln, 2000, p. 5), not only define the worldview of the researcher and clarify the

particular kind of qualitative inquiry that is being undertaken, they also determine how the research data will be used to address my research question.

To ensure the wheels of the study's epistemological underpinnings will turn smoothly as the research unfolds towards its conclusion, I seek to align my methodology, autoethnography, with the philosophic framework of interpretivism.

Interpretivism allows a researcher to "develop subjective meanings of their experiences" (Creswell, 2012, p. 24). As an interpretivist, I seek "culturally derived and historically situated interpretations of the social life-world" (Crotty, 1998, p. 67) and "describe and understand the participants' and/or researchers' meanings and understandings" (Koro-Ljungberg, Yendol-Hoppey, Smith, & Hayes, 2009, p. 694). An autoethnography, as a unique text, aims to shed light convincingly on "general, unfamiliar cultural processes" (Ellis et al., 2011, p. 283) through its focus on "data that are rare, under-studied" (Tracy, 2013, p. 135) in order to contribute in some way to new knowledge.

In this thesis, knowing or understanding is built through the use of a narrative text written in the first person, where the narrative mode is a "mode of knowing", different though complementary to the "logico-scientific mode" (Rutten & Soetaert, 2013, p. 329). Autoethnography, as a first-person, narrative approach to research, lies at the heart of my research design. In line with my epistemology, my methodological intention in this study is not to merely describe my "lived experience" but to understand my son's life and his death, to describe and understand that experience interpretively. Melissa Freeman (2014) understands the philosopher Gilbert Ryle's much-cited notion of "thick description" (1968) to be a "revisioning of what has been previously understood" (Melissa Freeman, p. 831). This revisioning is not a use of description as "contextual features" that organise my "seeing", but rather, revisioning

allows me to "see within the multiple spaces that come alive and are brought forth in the complexity of existence" (p. 831). For Freeman, "it is by seeking new ways to see that interpretive research helps mediate new configurations for this boundless web of meanings we inhabit" (p. 832).

With an instinctive fear of being subjective, and reluctant to simply report "my lived experience", I turn first to Habermas who, in *Knowledge and human interests,* (cited by O'Donoghue, 2007, p. 10) expresses the belief that qualitative inquiry conducted within the interpretive paradigm is inherently heuristic. Next, I turn to Moustakas (1990) who urges researchers to "respect their own questions and problems" and adopt a process "that affirms imagination, intuition, self-reflection, and the tacit dimension as valid ways in the search for knowledge and understanding" (Wall, 2006, citing Douglass & Moustakas, 1985, p. 40). For Wall, such an heuristic endeavour very much resembles the action of an autoethnography.

Wall's stance regarding methodology is a bold one, which I embrace. She regards methodology as one of the entry points defining the philosophic boundaries for qualitative inquiry, that it is just as important as ontological, epistemological and axiological understandings. She goes a step further, saying autoethnography is "less of a method and more of a philosophy, theoretical underpinning, or paradigm, aimed at restoring and acknowledging the presence of the researcher/author in research, the validity of personal knowing, and the social and scientific value of the pursuit of personal questions" (Wall, 2006, p. 6).

The kind of autoethnography I have adopted – critical autoethnography (Holman Jones, 2016) – is in keeping with my philosophical framework of interpretivism and a theoretical perspective of critical theory. Critical autoethnographic accounts are highly reflexive, written in the first, second or third

person. They "foreground a writer's standpoint, and make this standpoint accessible, transparent, and vulnerable to judgment and evaluation" (Adams, Holman Jones, & Ellis, 2014, p. 89). Such accounts operate by putting story and theory "into direct conversation … using the vocabulary of theory and the mode of story" in order to create "nuanced and compelling accounts of personal/cultural experience (Adams et al., 2014, p. 89). For Holman Jones (2016), the practice of critical autoethnography exemplifies three central concerns. Firstly, "theory and story work together in a dance of collaborative engagement" and share a "reciprocal, inter-animating relationship" (p. 229). Secondly, critical autoethnography involves both "a material and ethical praxis", and thirdly, "doing" critical autoethnography "engages us in processes of becoming" and because of this, shows us "ways of embodying change" (p. 229).

In a "reflexive methodology" (Gergen & Gergen, 1991) such as autoethnography, the researcher engages in continuous critical reflection on their positionality while the research is being undertaken. Autoethnography allows for "the production of new knowledge by a unique and uniquely situated researcher" able to offer "small-scale knowledge that can inform specific problems and specific situations" (Wall, 2006, p. 4). This challenges the traditional view of "knowledge production as independent of the researcher producing it and of knowledge as objective" (R. Berger, 2015, p. 2).

My philosophic positioning is inclined towards the critical, as it involves both social critique and the guiding of that critique towards questions about how social action might be taken – action that might "create social and political conditions more conducive to human flourishing than the present ones" – Finlayson (2005) explains that this kind of "practical intent" is both "diagnostic and remedial" (pp. 3-4), in other words, what is going on, and what can we do about it?

Autoethnography is aligned not only with my philosophical positioning within an interpretive framework but with my research aims. Autoethnographers view research and writing as "socially just acts", the goal being to "produce analytical, accessible texts that change us and the world we live in for the better" (Ellis et al., 2011, p. 284). As a methodology, autoethnography allows the kind of "personal challenge" that Moustakas (1990, p. 15) speaks of to explore both individual or personal meaning, and shared, social meanings. An autoethnographic approach allows me to ask the kinds of *"why?"* and *"how?"* questions an interpretivist asks, while at the same time framing my research in a social justice context and extending my research question to include the *"what should be?"* questions that a critical theorist asks (J. Thomas, 1993; Tracy, 2013, p. 48).

While I use critical qualitative inquiry as a theoretical perspective, using critical theory as a lens, I do not claim to work as a critical theorist. I work within a qualitative framework that has "accommodated" critical qualitative inquiry in the sense that Denzin and Lincoln explain, where the interpretive paradigm can include critical inquiry, and where these paradigms are each able to accommodate other types of inquiry (2011, p. 112). Autoethnography enables this kind of accommodation because it allows for a particular questioning of, and use of, my data. The idea of critique is inherent in my research goals. Both a perspective inclined towards critical qualitative inquiry and the use of a critical lens are appropriate for this study – since my topic is linked to questions about what might be done to effect change in young people's lives.

Since youth studies is often conducted from a critical perspective, a critical theoretical perspective also aligns with my conceptual framework (described in Chapter 2). A critical lens lets me examine the societal structures and contexts of my

son's life, and so addresses my research question. It enables me to illuminate the issues raised in this study, in a way that will, I hope, provoke further questioning, research, and action. This outward focus towards a social justice aim is crucial not only to my goals, but also to ensure this study warrants research attention (Staller, 2013, p. 410).

3.2 An evolving conceptual framework

The research design for this study is dictated by its autoethnographic approach, which had implications for my conceptual framework, which is derived from the discipline of youth studies, as explained in Chapter 2.

Youth studies provides both the backdrop for the "action" of this study, as well as the compass points of "sensitising concepts" (Tracy, 2013) I used as a provisional framework for this study's research design. Derived from my wrestling with my research question, the sensitising concepts, or "general signposts" (Leshem & Trafford, 2007, p. 96) that I used to set the study in motion, were : "normal", gifted, bullying, angst, dread, along with depression, addiction, drug use, paranoia. From a youth research perspective, I came to see that to build my research design around some of these concepts could be regarded as adopting a negative, problem-based approach – often disparaged in youth studies (Mørch, 2003, p. 51). Temptingly elegant and "easy" to use, my sensitising concepts supplied the "what" of my study but not the "why", and clashed with the transformative intention (see, for example, te Riele, 2010) in my research design. Even though I am not working in a wholly "transformative" qualitative research paradigm, as outlined by Mackenzie and Knipe (2006, pp. 198, Table 191), I wish, in however small a way, to contribute to positive change in social policy and practice (Denzin & Lincoln, 2011, p. 106).

However, once I began writing the autoethnography, I realised that my conceptual framework could evolve. Autoethnography is a journey into the unknown, and by keeping myself open to what emerged as I undertook this research, striving to be continuously reflexive, the direction of the research became determined by the autoethnography itself – and not by any predetermined outcome or predetermined conceptual framework.

In an inductive study such as mine, with the "staged" approach that is autoethnography, "multiple, and evolving, conceptual frameworks" are possible (Leshem & Trafford, 2007), helping a researcher to make "theoretical links between extant research, current theories … interpretations of findings and conceptual conclusions" (2007, p. 101). A conceptual framework can emerge "from … reading, personal experience and reflection upon theoretical positions toward the phenomenon being investigated" (Leshem & Trafford, 2007, p. 96).

As the writing of the autoethnography proceeded, with its deep reflection, reflexive writing, and examination of texts, poems, memorabilia and other data, a more nuanced conceptual framework was needed. The conceptual framework of youth studies had been the handrail I held on to while exploring one aspect of youth studies in more detail: youth mental health. As the study proceeded, I had to be true to the autoethnographic revelation when it came: overwhelmingly, more than "bullying" and "addiction", it was "shame" and "stigma" that needed to be foregrounded, as they lay *behind* so many of my original sensitising concepts.

True to form, my initial preconceived *sensitising* concepts fell away like scaffolding. In their place, what I would call *organising* concepts – the "through-lines" or leitmotifs of this study – emerged as I wrote. They were centred on "knowing", and its converse, "uncertainty". These leitmotifs proceeded to arise in

pairs. *Hope and fear; isolation and belonging; absence and silence; shame and stigma.* Some are used in the Discussion (Chapter 6) some in the Literature Review (Chapter 2). They helped me arrive at the "why" in my research, critiquing the societal structures serving youth – the milieu in which my son's difficulties arose.

Using the conceptual framework to make sense of my data (Leshem & Trafford, 2007, p. 99) and trusting to the writing process to allow these thematic concepts to emerge organically, I did not use qualitative analysis software. The outworking of my conceptual framework lead me to a very personal examination of issues surrounding mental illness, and how we might begin to look at these issues in a more holistic way. Autoethnography involves not so much the reporting of "a happening" as the expression of "a state of affairs" (Brinkmann, 2009, p. 1378). The phrase, "state of affairs" resonates in youth cultural studies, where Australian policy concerning young people is termed "youth affairs". What befell my son is but one of many stories in the larger context that describe the "state of [youth] affairs" in Australia.

3.3 A research design incorporating autoethnography

In my research design, autoethnography dictated every step: the ethical ramifications of my approach, its dialogic potential, critique of the methodology and its use of subjectivity and reflexivity. As a method, autoethnography is "both a process and a product" (Ellis et al., 2011, p. 273) and consequently the term, "autoethnography", has a dual meaning, referring both to the research *process*, and to the resulting research *product* (Meerwald, 2013). The success of an autoethnography depends not only on its theoretical positioning within research traditions, but also on how well I, as the researcher, make it work in this dual way, as "both a method and a text" (Meerwald, 2013).

I arrived at my research design in a slightly unorthodox, non-sequential manner. Though separated from each other as distinct chapters, my research, in the form of the autoethnography, and the conceptual framework, in the Literature Review, were developed alongside each other during the research process. In autoethnographic practice, the autoethnography itself performs the role of both a "results" chapter and an "interpretation" chapter, as autoethnography performs the simultaneous acts of being both the data and the analysis (Ellis et al., 2011, p. 279).

In order to construct the autoethnography, I had to be certain that a "cultural context research design" would suit my research, rather than a "story research design" based on narrative inquiry (Hamilton, Smith, & Worthington, 2008, p. 24) and I concluded that a "cultural context" research design would be aligned with my theoretical perspective. Due to the nature of my "data", and the non-linear nature of the narrative text, a story-based research design would have been too rigid. An autoethnography does not set out with fixed parameters in its narrative structure. It does not have a commitment to the conventions of story, with a beginning, middle and end. The action of an autoethnography is a non-linear yet "staged" process (Leshem & Trafford, 2007, p. 99) but the stages of its production are not sequential in terms of plot.

Autoethnography as a method required me as the researcher to transparently and deliberately position myself in the autoethnographic research "product", visible and vocal, an "artefact of textual practice and authorial choice" (Gannon, 2013, p. 232) and installed in the text. Using the first person, the researcher as "I" refers to a self, positioned in various dimensions, whether that be in time (present or past), or in various social contexts (work, parenthood, or artistic endeavour) or existentially suffering, striving for understanding, seeking meaning.

At the same time, I had to steer the research account outwards towards society, orienting it towards a cultural context, making that focus primary, always contextualising my own experience by grounding it in those larger cultural contexts (Staller, 2013, p. 410).

A kind of dual consciousness is fundamental to the operation of an autoethnography. The researcher's self, both inward- and outward-oriented, operates within the autoethnography's "story" and within its research procedures. Performing this double act enables the researcher to posit questions in wider societal contexts. Here is what autoethnographic scholars mean when they define the "I" in autoethnography as a "*cultural* I" – coupling the personal pronoun with the research intent of studying culture. This use of the *cultural* "I" rather than a *narrative* "I" (Ellis, 2004; Hamilton et al., 2008, p. 24) distinguishes autoethnography from other genres that use the personal pronoun. Some autoethnographers abandon the *narrative* "I" altogether; others speak of a *storying* "I" (Frank, 2012) – but all use the self as the "narrative resource" (Frank, 2012, p. 36).

At the crux of the dual process/product nature of autoethnographic work is how transparent a researcher is about their "narrative construction" (Barone, 2007, p. 456). As a methodology, autoethnography involves a "recasting of data into storied form" (Barone, 2007, p. 454), in order to produce a text capable of achieving cultural meanings, or "dual experiences of individual and cultural activity" (Grbich, 2013, p. 118) for both the researcher/researched and for the reader.

In a qualitative study, the "research process, epistemologies, values, methodological decision points, and argumentative logic" need to be made "open, accessible, and visible for audiences" (Koro-Ljungberg et al., 2009, p. 687). Autoethnographic research requires the researcher to write about the process of

writing "and the context in which that writing occurred" (Wall, 2008, p. 40) in order to demonstrate how the autoethnography has arisen from the researcher's reflections and reflexivity. Such discursiveness about process is traditionally left "behind the scenes" but in qualitative studies, "methodological transparency" (Koro-Ljungberg et al., 2009, p. 687) can contribute to rigor (Bridges-Rhoads, Van Cleave, & Hughes, 2016, p. 538). However, autoethnographers have to balance "*telling* (about autoethnography's history, methods, responsibilities, and possibilities)" and "*showing* (doing the work of autoethnography here on these pages …)" (Holman Jones, 2008, p. 207, original emphasis).

3.3.1 Ways to deal with autoethnography's subjective account of the world

Working qualitatively, autoethnographers regard as normative a subjective, and not an objective, account of the world (Peterson, 2015, p. 226). While overtly acknowledging their subjectivity as an inherent part of their "positionality", autoethnographers sometimes still need to defend their subjectivity as a valid stance from which to write research accounts, even though it is almost 60 years since Michael Polanyi (1966) argued for the value of subjectivity in research (Ings, 2014). Autoethnographers also frequently need to defend, almost like activists, their aim of "re-establishing the centrality of personal experience and identity in the social construction of knowledge" (Goodall, 2004, p. 187). How the self is used is key to how critiques of autoethnography are addressed. The kind of subjectivity autoethnographers use is one where the self is used in the sense of an opened-up wide-angle lens. Hamilton (2008, p. 24) speaks of an "ethnographic wide-angle lens with a focus on the social and cultural aspects of the personal".

Peshkin encourages those writing in the first person to actively and "systematically seek out subjectivity while research is in progress" (Peshkin, 1988, p.

17). For further exploring subjectivity, Peshkin puts forward an array of "alternative lenses": positionality, patterns, time, emic, ideology, themes, metaphor, irony, and silence (2001, p. 242). I have used several of these alternative lenses, which I will shortly enumerate, but hasten to add that I found myself using these alternative lenses intuitively, and, once I found Peshkin's article, turned them into formal ways to structure the autoethnography.

My *positionality* has already been outlined in Chapter 1. *Silence* becomes an organising leitmotif in the autoethnography itself. *Metaphor* forms the fabric underlying many of its interpretive passages. *Time* plays a role in the sense of asynchronous time, in how I was "out of synch" with events in my son's life as they unfolded. *Irony* is apparent in how I had worked in youth studies yet could not apply its research to my own circumstances. With these lenses at my disposal, I felt a soaring sense of freedom or rather, permission, to write.

At the outset of my research, discovering Richardson's "Writing: A method of inquiry" (1994) had lead me to hope I could find a methodology that would accommodate my "writerly" self in my research. In autoethnography I could see a way to also incorporate, or accommodate, my "youth studies worker" self, my "poet" self – as well as my "mother" self – and eventually my "researcher" self.

This idea of a multiple self is explained by Cortazzi (1993) as "the self now recalling then, the self now interpreting the self then from the present self's perspective, the self now thinking of possible future selves, a possible future self looking back to now to the present self seeing it as if in the past …" (Cortazzi, 1993, p. 12). This is also an explanation of the operation of autoethnography as a reflective and reflexive research practice. Finding the right angle for using these several selves at my disposal was revelatory. I came to see the idea of a fluid self as useful and not

problematic, as it allows not only for expanded perspectives, but also for the autoethnographic reflexivity to operate in an on-going way while the research was undertaken.

This fluidity of the self is not indicative of instability, but rather, impermanence as the selves move through time. Adams and Holman Jones speak of autoethnography in terms of "uncertain, fluid, and becoming subjectivities" (Adams & Holman Jones, 2011, p. 110). This helped me to trust the autoethnographic method as it quite literally reflexively "unfolded" into storied form. It was liberating for the writing process that my voice was not fixed in time or by time, but mutable, altering as my perspective, as "I", could move between different modalities of self.

3.3.2 Voices in this thesis

Conventional studies are peopled by figures that are deemed to have "authentic voices": participants, whose disembodied voices are the data that is "hallowed … as if their words – supposedly uncontaminated by theoretical interpretation – can serve as a foundation of knowledge" (St. Pierre & Jackson, 2014, p. 715). In an autoethnographic account, we read not interviewees' but the researcher's voice. I am not only the researcher in this study but also the only overt "participant", being both the informant "insider" and analyst "outsider" – and also the research instrument "absorbing, sifting through, and interpreting the world" (Tracy, 2013, pp. 2-3). However, my son's voice is included too, through recall and the use of his own writings, and so he becomes a silent presence in this thesis. In his absence, I have also had to be his ethical defender and privacy commissioner, mindful of the ethical implications for how he is represented here, and try to do so in a way I imagine he might have approved. During the course of the research, the "voices" of my son, and of my self in the present, the past, and my self in an analytic process of

interpretation, each in turn fully represent or body forth the respective *verstehn* for this study.

3.4 My use of data in this thesis

For their data, autoethnographers draw on memory as well as data from their own life (diaries, notes, memorabilia, art, or objects). Such retrospective data might be disparaged in some quarters, but in autoethnography and other "narrative" strains of interpretivist research, such as narrative inquiry, life story, and collective memory work, using retrospective data is vital where the focus is on the *meaning* of the past event, within its particular social cultural and historical context (Snelgrove & Havitz, 2010, p. 345). The purpose of using the past is for increasing understanding, rather than for the discovery of underlying social facts.

My data therefore consisted of small sets of textual data relating to my son, including his poems and other writings, instead of interviews, surveys or questionnaires. I also drew on my own writing – notes, journaling, poems. My autoethnographic account composed from this data along with my recollection and critical reflection then became a further iteration of that data. In this way, the product of autoethnographic research – the storied account itself – becomes data. Simultaneously, as the autoethnographic process unfolds, data analysis begins. This "performance" of autoethnography is part of its unique way of doing qualitative data analysis.

Qualitative data analysis – an equivalent term for the positivist's "coding" of data – has been described by Lather as the "black hole" of qualitative research (cited in St. Pierre & Jackson, 2014, p. 715). I will delve deeper into the nature of qualitative data analysis in Chapter 5, where I travel into the "black hole" of my data (Lather, 1991, p. 194), a black hole emblematic of both the process of mining for meaning,

and of the exploration of a kind of interstellar space in the hopes of finding meaning, or at least explain all the lacunae in my own understanding of my son's life. For now, to explain "data analysis" as a part of my methodology, it is as if the shades of grey, in what I had always known to be black and white, became increasingly apparent. My chosen research method made me become tentative, especially about coming to any definitive "conclusions" from my data.

Autoethnography's data is unconventional, since, as a method, from collection to analysis, it is essentially "not 'data-driven' (using induction) nor 'hypothesis-driven' (using deduction)" but instead, is "driven by astonishment, mystery, and breakdowns in one's understanding (abduction)" (Brinkmann, 2014, pp. 720, 722). My autoethnography hinges on what Flyvbjerg (n.d.) has called "tension points" – deliberately chosen, emblematic, critical or "living moments" (Shotter & Katz, 1999) in my life experience and/or my son's life. Brinkman (2014) calls them critical "instances". They explain the non-linear and break-step structure of the autoethnography (Chapter 4 and Chapter 5). "Critical instances" are for me autoethnography's unconventional data – "any material we use to think about an astonishment or breakdown in one's understanding … of life events, big or small"; there is "no line between life, research, theory, and methods because research is part of the life process" (St. Pierre & Jackson, 2014, p. 717). In this way, in the autoethnographic account, my life and my son's life intersect, as my youth studies self with her outmoded "youth transitions" views of youth, comes face-to-face with 21st Century youth culture in the person of my son.

It is here in this state of breakdown that I worked. It is also where I found a stance for my "poet" self which I can best describe in sociologist Andrew Abbott's (2007) words, as a lyrical approach to research writing. In a lyrical approach, the

researcher is focused on the image, rather than on "sequences of events" that in purely narrative accounts explain the phenomenon of interest. There are some parts of the autoethnography where poetry was the only way to write. Using the poetic image is to me to use a telescopic, condensed, compressed form of writing, handy to convey the rich meanings behind a situation, event, episode or instance in my or my son's life, and a way to succinctly convey cultural, contextual knowledge into the small space of a thesis. For Abbott, images in this sense are "viewed in different ways, through different lenses, to evoke the sources of the writer's emotional reaction" (Abbott, 2007, p. 76).

3.4.1 Using poetry as data to contribute to meaning-making

I have used my own poetry and my son's within the autoethnographic account if doing so quickly and or concisely covers the narrative territory, or usefully symbolises certain themes. Some of my data are in his own handwriting. For me, poetry is not an imaginary world concocted out of a romantic image, but arises from a deep place in my life – indeed, perhaps even the same place where "Truth" and "Authenticity' and "Sincerity" might dwell were such abstracts allowed a presence in our postmodern world. A successful poem or autoethnography contains threads leading outwards, towards if not universal truths then at the very least towards contexts wider than the writer's purview – with which the reader can relate. A well-written poem transcends its author's subjectivity, or its topic's narrow focus, when it conveys a universality that resonates with its reader and contributes to meaning-making. The methods for making sense of experience are always personal, as Dewey has famously said (cited in Denzin, 2010b, p. 87). A poem can convey precise and multi-faceted meanings. To adapt Richardson, "writing [poetry] is also a way of 'knowing' – a method of discovery *and* analysis" (1994, p. 516, emphasis added).

Instead of dealing with "data collection" and "data analysis" as separate and separated activities, in autoethnographic research, data collection, data analysis and interpretation can happen during the writing of the autoethnography. This is due to the heuristic quality of autoethnography as both process and product, as method and text (Ellis et al., 2011, p. 273; Humphreys, 2005, p. 841; Meerwald, 2013, p. 45; Reed-Danahay, 1997, p. 9; Spry, 2011, p. 501). Earlier seminal research by Richardson (1994) laid the foundation for this approach, emphasising that qualitative researchers do not 'write up' what has already been found or discovered. Rather, the writing itself is a form of analysis, or as subsequent researchers have stated, "performs" the analysis. It is in writing that the data collection for an autoethnography primarily occurs. To me this explains a key difference between quantitative and qualitative methods regarding data: the former is focused on data and then the writing happens, while the latter is focused on writing in order to capture the data.

3.5 How this study seeks to address evaluation criteria

I have described below the qualities I sought to achieve in order to make my work rigorous and scholarly, relying on a variety of sources about evaluating the reputability of qualitative inquiry. Settling on a single set of qualitative evaluation criteria was somewhat problematic, as scholars continue to debate what the criteria for evaluating qualitative research should be. In qualitative research conducted in an interpretive paradigm, a positivist set of evaluation criteria – the "holy trinity" of "validity", "reliability" and "objectivity" – is replaced by one prime criterion for good autoethnographic research: credibility (Miyata & Kai, 2009, p. 66).

3.5.1 Credibility in autoethnographic research

Evaluation becomes very personal when the researcher/autoethnographer is judged for the credibility of their written account (Ellis et al., 2011, p. 282). How credible is my old "youth studies self" whom I brought to the inquiry initially? The "situatedness of knowing, the idea that we understand only in context" (Willis, Jost, & Nilakanta, 2007, p. 153) led me forward into territory where I experienced considerable changes of perspective and insight while undertaking my research, as my autoethnographic self emerged. To me, this "proves" the way autoethnographic research achieves its purposes in social science research, where the goal is to achieve *verstehn.* My slim story, its "evidence" or "facts", rest in a narrative construction, and for its credibility, that narrative relies not on "coding" or indeed, decoding, but instead relies on the account itself being one that a reader at the other end of the text will receive as credible.

In their overview of validity issues in qualitative research, and focusing on ethnographic reports, Altheide and Johnson (2011, pp. 586-587) place the word "evidence" in ironic quotes in discussing their criterion of "the spirit of evidentiary narrative". Credibility here depends on whether or not the "evidence" was "good enough" and whether there was enough evidence relevant to the topic. In their terms I have striven to write "a narrative that is appropriate for the purpose-at-hand" (p. 586) which is "contextualised" for this project.

3.5.2 Verisimilitude and resonance as an aid to credibility

Instead of setting out to make hard truth claims epistemologically, autoethnographers seek to create verisimilitude (Stanley, 2015, p. 148) or an "effect of reality" (Ellis, 1999) that will convince the reader of the credibility of the research. The term verisimilitude helps me understand the importance of presenting

"ethnographically driven data" (Pelias, 2004, p. 11) with integrity. I had to be as honest and as self-critical as I could be to contribute to the autoethnography's credibility. Although my account does not "map or mirror the world" it strives to achieve "an undergirding sense of verisimilitude (Gergen & Gergen, 1988, p. 40).

In critical autoethnography, the aim is to achieve a kind of engagement with the reader that is cultural more than personal. An autoethnography, although unique, should be able to shed light convincingly on "general, unfamiliar *cultural* processes" with which a reader can engage (Ellis et al., 2011, p. 283, emphasis added). I was concerned that paying too much attention to resonance might lead me to an over-reliance on evocative writing, reminding myself that my approach was *critical* autoethnography, not *evocative* autoethnography. A focus on critical instances, episodes and vignettes helps the account to contribute to *meaning*-making; they are not deliberately chosen for *feeling*-making.

3.5.3 Reflexivity as a quality control measure

Autoethnographers mediate their subjectivity by the practice of reflexivity, a form of "self-appraisal" on the researcher's part that performs a role of quality control in autoethnographic research. Such researcher reflexivity, as a kind of self-questioning and "checking-in", became for me a prime means for critical reflection, which was crucial for conducting my research ethically. I saw reflexivity as a kind of organising ethical consciousness to accompany me in writing my way through difficult material. This also involved being transparent about my positionality. This "consciousness" and conscientiousness I see as part of researcher reflexivity as a practice. I believe it helps me gain the reader's trust and ultimately contributes to research rigor. This rigor entailed a constant questioning of my own assumptions and allowing a "re-visioning" of my own ideas even as I wrote them. In this way,

reflexivity to help me to "maintain the balance between the personal and the universal" (R. Berger, 2015, p. 2).

3.5.4 Crystallisation as triangulation

An autoethnographer must do more than tell stories but give a scholarly and justifiable interpretation that does not rely solely on the researcher's opinions but is "supported by other data that can confirm or triangulate those opinions" (Duncan, 2004, p. 5). How then to achieve this triangulation, when qualitative researchers eschew the positivists' mechanisms of triangulation? I strived to achieve the kind of narrative triangulation that Richardson calls "crystallization" (1994, p. 522). This kind of triangulation is also discussed by other qualitative scholars (Ellingson, 2008; Saukko, 2003). Substituting the image of the crystal for the triangle, the text needs to be able to undergo transmutations within the narrative frame, and allow for multiple viewpoints despite the singular vantage point of the autoethnographic methodology (Saukko, 2003, p. 29). What I strived to achieve was the multi-faceted, refracting light of crystallisation, which, when shone on issues, results in a fractal research product, where "proliferations, crossings, and overlaps" work together in the final autoethnographic text (Lather, 1995, pp. 55, 58). My understanding of these ideas is that, taken together, they explain the creation process of an autoethnographic text. For me two word sums up this process: fractal, and refracting. For me the process of writing an autoethnography was one of pouring my story through the "refracting" lens of autoethnography.

3.5.5 Meaningful coherence, aesthetic merit

The idea of "meaningful coherence" is one of Tracy's (2010) "big tent" criteria for evaluating autoethnographies. Judicial selectivity dictated what to include or exclude from my "story" so that the text would allow meaning and interpretation to

come to the fore, yet also be aesthetically pleasing. In my study I use a variety of techniques to present text, including poetry if a poem met the criterion of contextual relevance. Tense varies from present to past, depending on contexts. I strived to avoid a disjointed presentation of material while replicating its dissonant nature.

In the end, an autoethnography should be able to achieve what a single case can achieve: highlight an issue in new way – perhaps, for others to study subsequently. By seeking to focus on salient aspects of my experience and by seeking within that experience the "data that are rare, under-studied" (Tracy, 2013, p. 135), I aim to achieve a text that will contribute in some way to new knowledge.

3.6 Ethics as normative attention: A way of knowing

Ethics as an evaluation criterion is discussed here, where it is inextricably bound to autoethnographic practice. An autoethnography stands or falls by the way it meets ethical standards and the ethical challenges of this particular study loomed large at the design stage. I needed to be mindful always of ethical issues as I wrote. I developed "a way of knowing that is contextual and narrative", using a "normative attention" (Schwandt, 2000, p. 204) as a guiding stance that I believe is a component of both ethical research and of autoethnographic reflexivity. The idea of paying attention in this way helped in what might otherwise have been a paralysing process of endless self-questioning and doubt

Several texts about the ethics of autoethnography guided my work. I relied on Tolich's (2010) prescriptive guidelines for autoethnographers, and on Australia's National Health and Medical Research Council's *National Statement on Ethical Conduct in Human Research* (2007) referred to as the NS. Schwandt's (2000) advice on developing "an ethic of closeness, of care, of proximity, or of relatedness, morality" provided detailed help as I considered what the impact of my work on

others might be, as I strived to practise an "ethic of care"(Denzin & Lincoln, 2000, p. 9). This involved reflecting deeply about my relationship with others as I wrote, and about what the impact of my story on them might possibly be.

Particular ethical issues pertain to ethical practice in autoethnographies. At first glance, autoethnography would not appear to imply the use of other people's data. However, other people's stories are often told in the telling of one's own. There are many people who were deeply involved in my son's life, and in giving my perspective their stories and identities might also be unwittingly revealed. To avoid this I have tried as far as possible to convey only my perspective and to avoid naming or describing others.

A definition of confidentiality as the "obligation of people not to use private information – whether private because of its content or the context of its communication – for any purpose other than that for which it was given to them" (National Health and Medical Research Council et al., 2007, p. 88) was relevant to my reflections about the use of others' stories. In advance of writing, I strove to reach clarity about what the issues of privacy and vulnerability might be in my research, and to whom they might apply. I have tried to honour the principles of privacy, confidentiality and anonymity throughout the conduct of this study (Brooks, te Riele, & Maguire, 2014, pp. 38, and 128). This was a deliberate practice of anticipatory ethics, by which I tried to anticipate any need for prior consent from others who might be "written into" the autoethnography in any way. I kept Tolich's 10th guideline as a blanket rule of thumb: "assume that all people mentioned in the text will read it one day" (2010, p. 1608).

I considered various ways to ensure confidentiality and anonymity, such as changing names, adopting a nom de plume, and "decoupling of events from

historically and geographically specific locations" (Saunders, Kitzinger, & Kitzinger, 2015, p. 622). However the "idiosyncratic details of a case" (Saunders et al., 2015, p. 627) could potentially make others implicated in my story unidentifiable. I considered changing my own and my son's names, but as Tolich (p. 101) point out, disguising names seldom works in autoethnography, since the story itself can make participants identifiable or make participants potentially identifiable to each other. Much of our son's story is well known to others and to those who know me. Therefore I decided to write under my own name, and for the same reasons, our family decided against anonymising François' name. My husband felt it honoured him more to use his own name in his own story. I concentrated on being mindful that the ethics of autoethnography centres on reducing possible harm to others, and used as my guiding principle a determination to minimise harm to others in the telling of this account.

3.6.1 Autoethnography and the practice of relational ethics

"At issue is how to answer the fundamental question, How should I be toward these people I am studying?" (Schwandt, 2000, pp. 203-204). I endeavoured to keep the feelings of family and friends in mind as I wrote what at first glance would seem to be an apparently "self-contained" autoethnographic account. In practising relational ethics, the autoethnographer values and respects above all their relationship with others and with their community (Ellis, 2007, p. 4) and is mindful that these others are invariably also always present, either as active participants or as "associates in the background" (Tolich, 2010, citing Morse, 2002; pp. 1599-1600). A huge restraint on any autoethnographer comes in the form of Tolich's warning that "the topics they choose might harm people" if not immediately then perhaps at some time in the future, and that "no story should harm others" (Tolich, 2010, p. 1605). There is an ancient power in "story", a power that is also present in autoethnographic accounts,

which are therefore capable of harming other people. Writing an autoethnography involves balancing these risks and harms against the benefit of getting the story told, balancing what I tell against what I can only speculate others might, or might not possibly construe from what I tell.

Before writing, I considered the problematic nature of having to seek retrospective consent. How then could I write, if my story might offend in ways I did not intend or could not anticipate? In the end, as I wrote, I strove to practise an alertness about the presence of others in my research, and tried as much as possible to exclude other participants.

In the 10 years since my son died, I have journeyed through grief and a sense of "permission" to write this account is strong – but whose permission have I been given and whose permission do I seek? My husband and surviving son, in their earnest belief in my scholarly pursuit, urge me to write what I like, but they might well be putting their own best interests on hold in saying this. Futhermore, François himself is not here to consult for his permission and approval. What exactly is that relationship, as I write about my son? Some, on hearing about my topic, invariably say, *You're so brave doing this research …* but I feel an unspoken question lurks behind their words like the proverbial elephant in the room: *How can you possibly study a son who has died?* In his absence, I re-imagine him, pondering what his response might have been to this or that dilemma in my research. Would he mind if I told this or that about him? This becomes a strangely dialogic process, as in writer/academic David Carlin's short piece, "Do you mind if I invent you? (2009).

For some time, a question remained in my mind: *In writing my son's story was I violating some taboo?* I believe that writing about my topic is helpful, culturally, in other words not for myself, but for others. In the same way, people "read poetry

because they are looking for someone unafraid to give voice to what is experienced in this world" (Cheryl Howard, *Poetry Matters* (26) 2016).

To be effective and of value, my autoethnography needs to "measure up" to the above criteria. Spread over two chapters, the autoethnography that follows will chart the course of a disjointed journey both in my past life and in the course of undertaking this study, with the purpose of contributing to an understanding of contemporary youth in Australia experiencing mental illness, presented from an individual perspective.

Chapter 4 will outline a chronology of events and of coming to know the facts about my son's situation, while Chapter 5 will reflect on and interpret that experience in a wider social context. Both chapters form what I refer to throughout the thesis as "the autoethnographic chapters".

Chapter 4

My chronology of knowing: An autoethnography

4.1 Part 1: Normal, Everyman, LIFE.

This is my chronology of knowing. It outlines how I came to know about what befell my younger son, the antecedents of the mental illness that often played havoc with his life, and my knowledge about the true nature of his predicament. The "chronology" of what I came to know was parallel but not equivalent to the actual chronology to events in my son's life. There is much about his life I only came to know about later – even though I am "mother".

4.1.1 Mother was wrong

Mother is always right, said a sign on our fridge. That was Rule 1.

Rule 2: If mother is wrong, see Rule 1.

My family had often joked about this fridge magnet. We were big on logic but not on rules. Recently I threw the fridge magnet away. I had been wrong in so many ways. Authoritative parenting had not been my strong point. In rearing my children, I

had often felt a need to compensate for the absence of grandparents, aunts and uncles in our sons' lives. I had felt disempowered at times, in a new country, and, in my own family, I sometimes felt I was surrounded by people cleverer than me – sons who could out-argue me, with minds sharp as razors, whose wit and reasoning defeated my own every time. A benign respect and disrespect could be said to have defined the quality of our relationships.

In 1986 we arrived in Australia with two toddlers and four suitcases, a map of the town we were going to live in, showing a railway line conveniently weaving its way through the suburbs upstream of the river to the town, and an article about the town dated 1956 from my grandfather-in-law's *National Geographic Magazine* collection. However, the passenger trains had ceased operating, industry had dwindled – as had our finances, after exporting ourselves and a crate of furniture across the planet to escape apartheid.

Our new town at night was silent. We were used to hearing distant gunshots, trains, and the snoring of a homeless man who slept outside our bedroom window in the night.

You can stay with your mother or you can come with me to Australia, my husband had said when the first state of emergency was declared.

You don't have to listen to him, my mother said, *You could stay.*

Your mother can come with us if she wants to, my husband offered. But she did not, and my sons never saw her again. The four-year-old had loved his granny fiercely, the baby – François – had no recollections of her. There was no Skype, no internet at that time. Letters took two weeks to arrive.

In the winter morning air, the baby's nappies froze on the wash-line during one of the coldest winters for decades. Within a week of our arrival, our children saw for the first time: the sea; a beach; a mountain; a river, and snow.

Slowly the elder child learns to sleep – he sleeps through the night for the first time in his life.

Two years later, the baby is four.

Mummy, what's an aunt?

He didn't he say "Mommy", I thought. He must be adjusting. *You have lots of aunts, and cousins, it's just that they're far away.*

For us, the loss of extended family and a close-knit circle of friends was immense. The consequences of apartheid are multiple, often invisible.

I begin every sentence in our new country with *We're South African but …* to make certain we are not classed as racists. Arriving unannounced at new friends one morning, the children and I are welcomed in with, *Ah, do come in … But please, don't talk about South Africa!* We are warmly welcomed by a church community thanks to a letter of introduction from our parish priest "back home". Walking into church on a Sunday was the only occasion in an entire week when I felt at home: the hymns and prayer books were the same even if the accents in which they were sung were different.

Here is François at three, a bright spark watching fireworks night, excitedly sitting down on the porch with large sheets of paper that he covers with rapid sweeps of his wax crayons, demanding, *More paper! More paper!* as he reels off sketch after sketch. As a child François seemed to be in a frenetic state of excitability for much of the time, an excitement dulled gradually over the years by the strict schools he attended. I now understand, from reading the work of Polish psychologist K.

Dabrowski, that this state of excitability is a characteristic feature in gifted children, who are said to have a way of experiencing the world that is "vivid, absorbing, penetrating, encompassing, complex, commanding – a way of being quiveringly alive" (Silverman, 1994, pp. 180- 203).

At eight he is riding his bike over an impossibly large stack of empty cardboard boxes. *That's too high!* the older children call out. *Never mind!* shouts François, flying over them, wheels spinning.

I seemed always to be having to take extra care with this child! Containing his intelligence and helping direct it into safer waters was a constant challenge for me as parent. Leaping from the garage roof at 10, he breaks his elbow in a complicated fashion.

This kind of break is only ever seen once in twenty years in London, the surgeon tells me. *I'll need to get a good night's sleep for this operation!*

François waits in hospital all night without food or water in preparation for the operation – without complaint, without pain relief. I sleep in a hospital bed beside him. He's stoic, this child.

After trying two different government primary schools, we decided to home-educate our children – a lonely undertaking for me although the children enjoyed it. I had the excellent guidance of a home education expert who gave us all the support I could wish for, but eventually I buckled under pressure for being so "unusual".

You're different enough being migrants, why make your sons even more different by home educating them?

I enrolled our small sons in a small school. On his first day François returned home saying, *Mummy, I had to correct the teacher's spelling on the blackboard today.* However they flourished, earning praise for their sociability and diligence.

Artefact 1: "I feel normal" (primary school worksheet, 1992).

The worksheet contains a stylised drawing of half a dozen round faces with various expressions. The child must link each face to corresponding words: *angry, sad, happy, worried, frightened, tired.* At the bottom of the sheet, the child must answer the question, *How do YOU feel?*

François has written: *I feel normal.*

The school was strict, old fashioned, and provided much needed stability in our lives, which privately were quite difficult, with the high interest rates of the 1990s making our mortgage impossible without my husband working double shifts for much of the week. I became some kind of single mother without the accompanying "perks".

Grandmother came to visit. My mother-in-law lived overseas and was an intimidating, eccentric woman well ahead of her time in all her beliefs. I often wrote letters to her about my difficulties in raising François, to which she responded with letters about the birds in her garden. I stood at the airport to greet her with the two boys in tow, spruced up for the occasion, keen to meet this grandmother they had last encountered in their babyhood. She stared at us all one by one, then fixed her eyes on the elder boy.

It's YOU I have come to see! she announced. François retreated behind my skirts and was quiet for the two weeks of her visit. I asked her about this hurtful greeting and was told my letters were so full of François, I must surely be neglecting my elder son. *But I was asking for help,* I tried to explain in vain.

By now it was 1995 and we had been in our new country for almost a decade. When the elder son was due for high school, the headmaster of the little school suggested I reconsider my decision to also move his little brother to the larger school. He begged me to let François stay to complete his last year of primary school and experience being a senior student before starting at the bottom of the pile in high school.

It would be so good for him to experience being a senior student in our school.

But I did not listen. Though far from our home, in another suburb where we often went to church, the new school had both a primary and secondary school and if both boys were that end of town, my own life would be simpler, as I now had a good job as information manager at the then National Clearinghouse for Youth Studies.

While the move was ideal for the elder child, for the younger, I believe this move helped set in train a concatenation of events.

Fast forward … A psychiatric interview (vignette, April 2005).

Psychiatrist:	*Give us a word beginning with the letter C.*
François:	*Concatenation.*
Psychiatrist:	*A real word…*
François:	*That* is *a real word.*

I am rolling up my sleeves to go on a school camp as parent help. The real reason I am going along to camp is to try to protect our son from the bullying he's experiencing.

Mum, if you ARE going to come on the school camp, then can you please make sure you don't say "Howzit". *Or* "Ja". *Or* jersey". *Or "*yukkel stukkel, gogga, braaivleis, tannie, takkies…"

The school camp was arranged to help children to get to know each other at the start of the year, but things had already started badly for my son at his new school. He changed from a confident, bright and witty child to someone nervous and quiet. At camp I was assigned a room to share with another mother. She did not speak to me – about our sons, the bullying her son was inflicting on mine, nor the steps being taken to address it. Intimidated by her silence, I watched myself say nothing to her. I was an outsider like my son.

My own relationship with my son faltered as I tried to address the bullying he was experiencing at school. Dropping him off one morning, I could hear a sing-song taunt begin almost as soon as he was the other side of the schoolyard hedge.

Frenchy Frenchy! You're a Frenchman, a Frenchman.

I leapt out the car and rushed through the hedge.

The last time François was French was 300 years ago, I thundered, also suddenly aware of the ridiculousness of my statement.

Mum, growled my son, *MUM!*

François had been used by my husband's family since they had arrived in the Cape in 1688. A common name in South Africa, in Australia, people seemed to battle to pronounce it. *Frank-oys?* they'd ask politely.... But now it was 1995, and our son's name was topical in a way he could not control. On 13 June 1995, the French

President, Jacques Chirac, had announced he would break a three-year moratorium on nuclear testing in French Polynesia. The French planned to conduct eight underground tests in the South Pacific or French Polynesia, particularly in the Mururoa Atoll, and protests in Australia were vehement.

You could be Frank, I suggested one afternoon. *Like your uncle Frankie.*

But I am not Frank.

He became particular about the cedilla: *Not Francois, but Françoi*s, he insisted. Punctuation had fascinated him from the age of three, as he was read to each night. *What commas are for? Why is there an exclamation mark there?*

The name Frenchy stuck.

I took an armful of research on bullying from my office at the Clearinghouse and handed it to the high school headmaster. He looked serious, promised to read it and put it down again on his desk.

Teachers suggested I make him more resilient, and this left me feeling it was my fault he was not able to stand up for himself. I took him to see a psychologist – but François went only once and after that he always resisted my suggestions he get help for depression, for anxiety.

At the start of the next term my son flatly refused to go to school, holding the bed sheets up to his chin, refusing to get out of bed. In explanation he told me a little more about the teasing. The destruction of his precious pencil box and crayons did not seem to me to account for the palpable fear in his eyes. I recalled the injury to his back, which had almost punctured his lung; he'd fallen against a fence post during a soccer game at recess.

The school implemented an anti-bullying program – with our son's class being the first to put it into practice. Things were smoothed over.

François, how about you move schools? I suggested he go to a prestigious school not too far away from where we lived.

Half way through writing the essay required for admission as a scholarship student, he put his pen down. *But mum. I don't have any friends there*! and refused to continue with my plan.

Again, I listened to him.

Artefact 2: "Normal": A high school English assignment, 1998

The task: Write an extended piece of prose telling a story.

In response, François wrote a 13,000 word novella titled *Normal*, about a man who would have been called Norman but for a typographical error on his birth certificate. Normal falls victim to random physical attacks and identity theft after being cloned.

Eventually, a crust formed around him at his school – a cohort of children stalwartly defended him. They became his strong, fiercely loyal friends. They skateboarded and did dangerous things on bikes together. They were resilient children who wore their caps backwards and defied whatever odds were thrown against them in their rural town: boys who protected and defended and championed their "Frenchy". An admiring group of girls formed protectively around him. I recall them crowding together on our sofa to watch the Baz Luhrmann version of "Romeo and Juliet" many times over. What exactly is so normal about adolescent angst that teenagers themselves so avidly enjoy its portrayal in fiction and in movies?

At this time, research on resilience was burgeoning and school bullying was attracting policy attention nationally – developments I reported on regularly in the Clearinghouse newsletter – which my sons would read at home. As a parent, I longed for the kind of *nationally* deployed programs I knew from my reading which could take a child out of their peer group for long enough for them to find themselves, for example through service to others. Research and programs like the United States' Search Institute and the Forum for Youth Investment (Pitmann, 2002) might have helped a child like mine, but their ethos seemed to find no foothold in Australia. I also could not interest our children in the youth development programs available to us – programs such as Scouts, Surf Lifesaving and The Boys Brigade. These programs were included in the early 2000 "AUSYOUTH" pilot program which made use of international ideas about service by youth to their communities. However AUSYOUTH was received very sceptically by Australia's youth sector, who dubbed it, "young people in uniforms". *I can't see AUSYOUTH helping even one of the young people I deal with on the street,* I recall an angry policeman saying at a regional launch of AUSYOUTH. The program ceased. I sensed an opportunity was lost.

I felt frustrated, with one kind of knowledge in my head, and another at my elbow. I was neither an academic with a voice, nor a bureaucrat with the ear of policy-makers who could make things happen and devise programs. "Greencorps" was the only youth service model available to young people, on a very limited scale. This very successful initiative was later "watered down" to be an all-ages program, and yet another youth development opportunity for Australian youth was lost.

In his matriculation year, François' teachers were concerned about his poor school attendance. To attract him back to his studies, he was invited to be part of an International Baccalaureate initiative recently introduced at his matriculation college.

Things improved. François pulled himself together and achieved remarkably high marks (96.8 overall) in his final matriculation examinations. However, he always kept one eye on his social life, which drew him like a magnet away from home.

Young men can be their own worst enemy, something keeps them silent when they should seek help. François was nothing if not stoic. I was always said to be resilient. Between the two of us, we were not the best at seeking help when something was wrong. Perhaps I relied too much on my sons' independence and resilience, trusting them to know what to do to help themselves. There is a large body of research devoted to resilience in young people, and a large number of early intervention programs have developed in schools over the recent years to help build resilience in young people.

"A caring, sensitive young man" is how our son's school paid tribute to François on his death. Yet our Australian way is to cover up sensitivity. Young tradesmen especially building workers are very much at risk of suicide; they are also told to toughen up, to "swallow some cement", metaphorically speaking. Does a kind of unhealthy stoicism masquerade as resilience? Does such stoicism have the life-saving qualities of resilience? I began to wonder, could this – a fierce stoicism – perhaps be the very thing that prevents help-seeking in young men? Right at the end of my study, new research on stoicism was published, showing stoicism could be a factor contributing to suicidal thinking and to a lack of help-seeking in men (Pirkis, Spittal, Keogh, Mousaferiadis, & Currier, 2017).

François was the most stoic person I have ever known, said his father. I could see François reach out to his friends in need, but could also see how gravely he lacked in caring for himself. The same high-spirited child that flew cartwheels over piles of

cardboard boxes seemed prepared to break any number of bones to perform a complicated skateboard trick.

Fast forward … "Ignore!" (vignette, 2000)

"*Ignore!*" said the graffiti that adorned many lamp posts and bus stops in our suburb.

I wonder who writes Ignore *everywhere*, I said laughingly to my son and his friend.

They laughed back. A little knowingly I thought.

Then I found a can of black spray paint next to the shoe polish, in the broom cupboard.

I chose to ignore it.

My son's short life coincided with a period of huge interest in young people's wellbeing. In the mid-1990s, through the influence of people like Jack Heath, now CEO of SANE Australia, the issue of youth suicide came to the fore, and a nation-wide youth suicide prevention initiative, AUSEINET was introduced in 1997-1998. Also at this time, academic writers like Andrew Fuller and Michael Carr-Gregg produced popular and ground-breaking books for parents on raising young people, and on understanding adolescence in contemporary Australia. Epidemiologist Richard Eckersley began to publish work on how young people's wellbeing in Australia was declining. Youth researchers Rob White and Johanna Wyn produced book after book on youth research. Professor Patrick McGorry's research at the University of Melbourne into youth mental health saw the development first of the Early Psychosis

Prevention and Intervention Centre (EPPIC), and then Orygen Youth Health and its "headspace" [sic] centre. Lead by Professor Patrick McGorry, headspace[1] as an innovative model of youth mental health service delivery was hailed as world best practice. Youth mental health research became the focus of the 2004 Council of Australian Governments (COAG) meeting, resulting in the 2006 National Action Plan on Mental Health, where a total of $4.1 billion was committed to programs, "the largest collective investment in mental health by Australian governments to date" (Council of Australian Governments, 2009). The funding had "an explicit focus on the promotion of emotional wellbeing, prevention of mental illness and early intervention" (G. Martin, 2006, p. 1).

Watching these developments, reading of them in my daily work, writing about them in my newsletter, I felt both optimistic and also a despair that this rich knowledge was at my fingertips but not available to me in my home life, in my home town.

In his teens, François was a gentle, quiet, reflective person capable of extremely sharp wit. His offhand, Keatingesque way of addressing people could confound as well as amuse – and sometimes, offend. Working as a school student at the local supermarket, and asked by supervisory during his tea break, *What are you reading a book for?* the rejoinder was swift and also fearless. *So I don't end up in a job like yours!*

His wit was perhaps part of a deflecting strategy he developed in order to protect a very vulnerable inner core.

[1] headspace (not capitalised) is an accessible, youth-friendly, centre-based mental health care program for young people.

Artefact 3: Comments in a high school report, 1997.

"François' biting wit and general knowledge frequently has a sobering effect on his classmates."

The maturity of his reasoning mind was not always matched with an equal maturity in his behaviour and I often regretted my lack of firmness in the face of his convincing logic: his reasoning ability trounced me on many occasions, making parental instructions difficult to enforce. He had a winning way of attacking my own reasoned "no" with his own patient and determined reasoning until he had converted my no into a yes.

Artefact 4: Extracts from a letter (personal communication, 2006)

"My memory is of a rather vague halo of hair, with golden and red glints reflected in it, surrounding quizzical and bright eyes that sometimes tuned out as he digested or wrestled with some inner idea but then suddenly came alive and blazingly into focus when he discovered a new angle or dimension.

"His appetite and zest for living was voracious …

"I associate the François I knew with life, with pushing boundaries and taking risks, with creating connections and creating…"

François' pessimism was of huge concern to me. There were often times I suggested he needed counselling, but he'd say, *Mum, you're using your social worker voice,* and refuse to go to appointments.

Mum, don't stress!

But something was not OK and its progression was slow, insidious, and most of all, invisible. "It" began before his teen years. When Martin Seligman's *The optimistic child: A revolutionary approach to raising resilient children* was published in 1995, I gave François the book's standardised questionnaire to measure optimism (Seligman et al., 1995, pp. 67-94). I was sobered by François' "results", which showed he was most certainly a pessimist. I took the questionnaire the next day to someone whom I respected and asked what she thought I should do as his responses were off the scale, quite literally.

I would not worry, she laughed. *He's so clever he probably skewed his answers deliberately just to get a reaction out of you!*

To my shame, I listened. *Yes, that would be right,* I reasoned with myself, *My sons are always a step ahead of me, everyone in our family is cleverer than me …*

As I write this, I have my 1997 diary open at the pages where I had noted my son's answers to the Seligman questionnaire. I checked them again. Alarm bells should have rung out loudly, proclaiming Depression! Pervasive depression! But, like the proverbial good seed that falls on stony ground, Seligman's questionnaire and the picture it painted of childhood depression slipped out of sight on my bookshelves among all the other self-help books I seemed to be accumulating.

At the age of 12, François asked for a guitar: not an acoustic guitar like his big brother's, but an electric guitar. He then set about teaching himself to play, and began to compose hauntingly beautiful short pieces. He would hear something and instantly

echo it with his long slim fingers finding their way instinctively over the frets. His music teacher at middle school met up with me after our son graduated to college: *I so miss François' music*! he said, genuinely sad. *You should fit out one of your rooms in your house for him. Let him have a studio of his own, buy him a sound system, he could work alone, that would be good, he is so advanced, he gets frustrated and held up working with other people, but let him work alone and he could streak ahead.*

As his teen years advanced, I sensed there was something wrong with François' behaviour and silences. Two family excursions to the movies resonated with me in a foreboding way that I could not pin-point at the time. The strange film, "Donnie Darko" (motion picture directed by Richard Kelly, 2001) is open to interpretation but seemed to me to portray a teenager's tortured premonitions of doomsday and his own mental illness. In "A beautiful mind" (motion picture directed by Ron Howard, 2001) a mathematical genius (the Nobel laureate John Nash), becomes obsessed with patterns but learns to overcome the voices he hears in his head. François had come with us to see these movies although he often chose not to take part in shared family events. We loved and "understood" these movies as a family, but what exactly had we understood?

Francois was hugely talented in mathematics, and achieved extraordinarily high marks at school and in national competitions, with an effortlessness that frustrated his teachers. His apparent careless disinterest in the subject belied the private battle he was waging in his own mind, which no one knew about. We learned only later about his own version of obsessive compulsive disorder, or OCD – and his battle with the number 4, with the square root of 2, with the numbers he saw in everyday surroundings. He would add the number of syllables in the words people spoke to him, and of the words he spoke in reply. No wonder he was so quiet.

For now he said nothing of these obsessions.

It was rare for him to disclose he needed help, but he complained a lot about pain. I sensed it was beyond what could be attributed to the rough and tumble of skateboarding. From the age of 16 until his death at 21, our son's pain was a background theme to his life.

A friend suggested we see one of the best diagnosticians in town. It was a short drive to his practice just up the road. I sat in the car and waited. Now that my son was over 16, I was locked out of areas of his life like medical appointments due to privacy law. I had taught my children to be independent and to go to their own dental appointments, to choose their own clothes, manage their own finances, select presents for friends. Now here he was managing his own health, a step in a positive direction. I felt pleased. But after seeing this new doctor, he returned to the car looking disappointed.

What did he say, I asked.

He says I need to look after my mental health! he said somewhat angrily.

We both stared at the road ahead. Eventually I started the car and drove us home. Without having heard what the diagnostician had advised, I did not know what action to take. We took no action. He was to look after his mental health.

Looking back, I am puzzled by my inaction at the time. Was it that both my son and I unconsciously feared the stigma I now know to be attached to mental illness? Yet we had both instinctively sought help through a GP. That instinct, to seek help through a medical practitioner, was well-placed, as a new government initiative was soon to prove. Launched just a few months after our son's death, the Better Access to Mental Health Care enabled GPs to act as "gatekeepers", -pivotal to the mental health care of Australians. GPs could draw up a "Mental Health Care Plan" for

individuals for referral to a psychologist, occupational therapist or social worker, with up to 12 treatment sessions (at that time) per year – at the Government's expense. Diagnoses able to be treated through this scheme included "anxiety disorders, depression and a wide range of other conditions, including psychotic conditions such as schizophrenia and bipolar disorder for which psychological therapy can be a useful adjunct treatment" (SANE Australia, email announcement, 2006). However, like the national roll-out of headspace centres, the Better Access initiative came into being too late for my son.

Diagnoses for his pain varied from arthritis to a form of ankylosing spondylitis, which often affects young men in their teens, to Osgood-Schlatter disease, which affects young people's participation in sports – including presumably, skateboarding, my son's preferred means of transport. Under any pressure, his anxiety levels rose, and then his hands stiffened. Like his uncles he was tall, lean and lanky, but stooped from the ankylosing spondylitis. His hands were almost always white knuckled, his long fingers and limbs, we were told, were the tell-tale signs of Marfan-like syndrome.

Getting his pain to be taken seriously by some medical professionals and allied health workers often proved difficult. Some dismissed his accounts of pain altogether and I experienced active hostility on one occasion, when I asked why the consultation with my son had been so very short. When pressed, the specialist said she was not interested in treating patients like my son, and implied the consultation had been a ruse by my son to get prescriptions for narcotic pain medication. I presume that suspicions such as this arose partly because of how he dressed. With deliberately dilapidated jeans and his offhand air, he met the criteria for some stereotype of youth that some medical professionals might hold. Research shows that patients, already

vulnerable with “stigmatised conditions” such as substance abuse disorders, are often on the receiving end of negative attitudes towards their pain issues, making them doubly vulnerable to receiving unequal treatment (Blay, Glover, Bothe, Lee, & Lamont, 2012; Meltzer et al., 2013).

Taking a gap year had been something François’ teachers had urged me to encourage, with an earnest look in their eyes I often saw in his teachers’ faces when they spoke to me about him, as if they, like me, were searching for something.

In some ways, it could be said the gap year before university provides the opportunities a “grand tour” might have offered centuries earlier. François’ gap year involved work, and moving out of home. Share-housing friends were keen for him to stay with them because he was “the only responsible one” and even offered to pay his share of rent when his job came to an end. But he could not bear the chaos of their lifestyle. Living with mum and dad had its advantages and he came home again. In the end, taking this year off between school and university put him out of step with some of his friends.

At university, however, Francois’ pain was understood, and he was allowed to write examinations in special sessions, since his hands became too sore for him to write within a two-hour time frame. He could write a bit, then go outside for a smoke and return to complete the exam. I bought a special haversack, designed to reduce back pain. Whatever its cause, his pain was real, frustrating, and inescapable for much of the time.

He seemed solitary at university, something I attributed to his shyness, but something distancing, something isolating, was settling in, and once set in motion, seemed to gather momentum, and he left after his first year. He had not failed any subjects, but the first year of university can be a time when students are “most likely

to experience social, emotional, and financial problems" (Moss, Pittaway, & McCarthy, 2007). A rocky start to university was "normal", I reasoned, knowing that the first year university experience can be difficult. I "knew" this from my reading at work, yet I did not know how to act on what I knew. He was a young adult now, after all.

At this time, both our adult sons lived at home to save money on rent and food, as they could not afford to live independently on a government youth allowance, or on student grants.

Our generation will probably be married and still having to live at home, one of them joked. We let them use the front of the house to have a semblance of adult life although they were under our roof, while we lived at the back. It was an arrangement that mostly worked.

What I read and reported on, at the Clearinghouse, each and every day, year in and year out, sometimes instilled in me a fear of the intractable "issues" in young people's lives, particularly in regard the plight of suicidal young men and women. I was brought up short one day, with these words in a student competition on mental health: "The last time I saw my brother he was cold and lonely in an empty room." Why did these words strike me so powerfully that I recall them to this day?

François was living at home, in an outside room. He was not cold … and despite his vegan lifestyle also probably not hungry – but certainly, lonely. His life seemed empty to me. He was a silent lad. While his older brother pursued his tertiary studies with a passion, François seemed adrift. I was increasingly asking myself, *What can I do, what can I do* in my head. I was aware that something was going wrong. I wanted action of some sort, even while I did not know what that action, solution, cure

would look like. I did not know what avenues of help were available to me because really, I did not know what was wrong in the first place.

Then suddenly, one day in 2004 François vanished.

It was Easter. I had no idea where he was. He did not answer his phone, which was unusual. At what point does one report a missing person? I rang hospitals. Desperate, on Easter Tuesday I found one of his friends who could help me find him.

I think I know where he is, he said. *I think I can get him to call you…*

Now at last, after five days, François called and asked me to meet him in town. He then asked me to drive him to his doctor. He was looking very agitated and unkempt: his hair was wild, and his warm winter jacket was full of grass seed. It seemed to have become a size or two too large for him. His mood seemed somewhat up-beat however; he seemed pleased to see me.

I'll wait for you, I offered, when we got to the doctor's surgery.

No, you don't need to, he said firmly.

But I decided to wait, and, at a nearby cafe, I reflected on how I was so relieved he had reappeared. I guessed he might be seeing the psychiatrist who also worked at the doctor's surgery, and when an hour was almost up, I ordered two large take-away coffees, and a chocolate éclair for François. When he emerged, he came to the car, and downed them eagerly. *Thanks mum!*

Then the surprise: *Please can you drive me straight to Centrelink?* He wanted me to fill out a form of theirs to say that his relationship with us had broken down irretrievably.

But it hasn't, I protested, alarmed.

Yes I know. But please, if you lie … I hate to ask you to lie, but you see then they will give me some income support to live independently.

I refused. *I am not going to lie, however much you want me to do so.*

Well take me to Centrelink anyway.

OK, I agreed, suggesting he also go to the employment advice bureau nearby. *E. works there, maybe she can help you.* E. was an old family friend. She rang me later to tell me that she had seen François at the employment agency, sounding excited.

I am so impressed with him Anne. He really is a fine young man. You should be very proud of him, she added. *And he was telling me he had been through such a terrible time lately, the worst period of his entire life, but he has managed so well. I really am impressed by him.*

I told her I did not know anything about the terrible time?

Oh, she said, back-pedalling … *I can't say. I am sorry. But you really should be very proud of him,* she added.

I am.

I imagined that my son might have experienced some dramatic trauma at this time but the facts around my son's disappearance that Easter are hidden from me, for now. Here begins my asynchronous knowing: I have come to know only now as I undertake this research that psychosis is very often preceded by some kind of trauma or traumatic loss (R. E. Hoffman, 2007). While I could deduce later that there was some initiating trauma from the hints from some professionals with whom I spoke, when I pressed anyone to tell me what had happened or what was the matter with my son, they said they would not and could not share it with me due to Australia's privacy laws. A vagueness would settle over the conversation, leaving me at a loss to understand my own son yet again. Yet always, whoever I was speaking with would say how very much they admired my son.

Then suddenly one Saturday morning, events of a kind I read about at work or in the newspaper began to unfold under my own roof.

François had told me the day before that he had decided to admit himself to a medical facility, "for detox", he told my husband. He had arranged everything, and could I please drop him off there? He insisted I must not accompany him. I watched from the car as he went to the entrance and sped up the stairs. *A tall, hurrying young man*, a phrase from a J.M. Coetzee novel came to mind.

Taking the stairs two at a time.

Going straight.

His hair combed so neatly into a ponytail.

With a haversack full of books.

Chomsky. Naoimi Klein. Pilger. Kerouac. Vonnegut.

A book of luminous things: An international anthology of poetry.

That night I slept with a grateful heart. It has come to this: a healing he has chosen. But my elation and relief lasted only hours. In the early morning came a phone call and the urgent words:

Your son's attempted suicide. Please come here at once. I am the psychiatrist. You must come to the hospital at once…

* * * * * * *

Facing his parents like a captured bird

eyes down, still

My son avoids me even in this

extremity of being.

We the parents

sitting shocked

are told

in no uncertain terms

he needs to be admitted to the psych ward. We have

no idea. We are not dressed

for this or any other news.

We are not able

to move.

My pyjamas under my coat

feel very shabby.

The hospital seems only just awake.

At 8 a.m. their lights are low.

The velvet pink suite nurse-station

is as still as still-life.

A frightened girl in uniform

appears, hovers with a file.

No way to start your shift on a Saturday

the psychiatrist says

reprovingly to me.

The psychiatrist speaks so quietly to me that I can barely hear him. Or maybe I have gone deaf with shock. *Stay with him.*

The psychiatrist's words seem to come at me a hundred miles an hour.

Don't let him out of your sight .

You'll need to take him to the public hospital.

Don't let him out of your sight.

It might take hours to admit him – and they will tell you to go home for a while, but stay with him.

Don't leave him – he might try to escape …

Escape? I have no time to ask for an explanation.

Read a lot, he tells me.

Read everything you can about psychosis.

SANE Australia has some good material …

Psychosis. His words come at me in staccato, all in the space of a few seconds, fast, in an almost muttering tone. I could easily have missed this sound advice, feeling stunned as I was. Some words stick: *Stay with him. Don't let him out of your sight. SANE Australia …*

Fortunately, I knew of SANE from my work life. Soon I'm on the other side of the phone ordering their booklets, on *Psychosis. Suicide.* For now though, my son stands before us as if he is dragging invisible chains, as if his hands are manacled and pressed together, though they are not. I can feel his anger. And his massive despair.

What we said to him that day is lost.

What he said to us was silence.

A few people filter through my vision just like the wan sunlight.

We seem to be waiting forever.

We are in a holding pattern but the plane we are in is not moving – the clouds are – the sun is, and shadows are – but not the people.

A security guard patrols the emergency ward. I do not recall how we got here. Thin plastic curtains touch much scuffed linoleum. Beyond them is the open door to the street.

They tell us, *Go home*. No, I realise, if the guard turns his back my son could escape.

Power is everywhere on tap but nowhere around our son. Power is never more clearly shown than in its absence: the patient's small bed. Everything in the hospital seems imbued with a grey light, as in a prison cell.

Passers by don't see the portal that is not a door. The door to the Psychiatric Intensive Care Unit is an entrance with a sign saying it is not an entrance. The door is recessed and flanked by two pillars like an Egyptian tomb. If you persist, you can sit and wait for the door to be answered. It will be opened to you if you are the right person: a close relation maybe.

At this place I have called a tomb there are officials, sad-eyed men with badges on their jerseys. Sun, disappearing over the cityscape for the afternoon, lights up the glass door briefly. I watch my shoes as I sit still… waiting to be allowed in. If I am very earnest will they let me in? Then I can wait in a waiting room, where an inner reception desk is walled in by glass. Inside are desks for about four workers but only one person is there. Her phone does not ring. She's typing. We wait. There are doors to cubicles – interview rooms. Sometimes they open and people come out of the small rooms. They might be parents like us. We all seem to avoid eye-contact.

Your son doesn't want to see you, we're told.

The man with the badge goes back into the walled reception room and vanishes.

We wait. After a while, he comes back.

All right, he has agreed to see you but only if I am present. You must not upset him because as soon as you do so, I will have to ask you to leave. And the interview will be over.

Our son seems even taller. He is still wearing the very old jeans that are falling off him he is so thin. Oh no it is because he is not allowed a belt. He holds them up a little. His eyes do not meet ours. He's looking away. In the 15 minutes we have to speak with him, he says nothing. He has gone completely into himself. Folded down like a cardboard figure of himself. He refuses to sit, and will not let us hug him. We're in low velvet armchairs. There's a low table. Nothing else. Nothing, even on the walls of this little square room. Opposite the door we entered through is another, leading to the inner workings of the psychiatry ward. Where the psyche is treated. Where the psychiatrists are. Where we cannot go. And where our son has a small area or room of his own.

I can feel his longing. He retreats. He's silent. We retreat. Each through our own doorways.

Back in the waiting room where no one is waiting, we ask if we can speak to his psychiatrist. This time, we're taken to a room no different from a car yard's waiting room. It is a perfunctory space, with no attempt at mimicking a sitting room or lounge. It's merely a passageway, with doors at either end facing each other as if their backs are turned against each other.

Three men – I am surprised to see they are wearing white coats – come and sit with us. Because of the awkwardness of the room, we are all sitting in a row, we face quite literally a blank wall.

They explain they have to keep him. We cannot get him back. He is theirs now. Our powerlessness sinks in. We are nothing. Useless parents. It is no good being proud. We listen but it's too hard to comprehend the magnitude of what is happening here. We wait. For more information. The men in white coats leave. A young nurse comes out. She is in her 30s perhaps. She has tears in her eyes. She puts her hands out

to us and her head drops forward as she hugs me; her long black curly hair makes me relieved that somehow there is some beauty, some gentleness in this hollow place.

Please, she says, *Your son needs to speak with a psychologist. He's been telling me his story and that is what he needs. He needs one now.*

She emphasises "now" as if she will not brook any argument about this, even though it is Saturday afternoon. *Now. Today!* she repeats.

I could probably find someone tomorrow, I begin but she interrupts, me, shakes her head.

No, now. Right now. Your son is such a lovely person, she adds, and her eyes well up with tears again.

In retrospect, I am grateful for this black-haired angel who was there to receive his story, given that he had not wanted to speak with us and I leave, promising the nurse we can find a psychologist to come and talk to him in the hospital. But will they let him in? Yes. And I do. A psychologist I knew who lived up on the slopes of a mountainside, known affectionately as "The Hermit", came to the hospital in this time of dire need, and did our family an immense favour in seeing our son intermittently during his hospital stay.

Our son is in psychiatric intensive care for a few days, but it seems like weeks. I have heard another young friend describe the experience of being in psychiatric care as being like living in a protective bubble, where all worries are taken care of.

We are allowed to visit once a day.

We feel like the enemy.

Somehow we go to work.

Then he is moved out of psychiatric intensive care and into the general psychology ward, only accessible through a labyrinth of passages that would be sunny if there were windows or skylights.

There's a smoking courtyard where a dull green sunlight filters down from a transparent roof far up inside this hospital ward that is locked.

Locked in...

Sitting there with our son I recognise an acquaintance – this is a small town. I try not to see him so he will not be embarrassed. Near us, another thin, energetic man seems to be praying, or reciting something. Nervous people. Stubbing out cigarette after cigarette.

François' stay in hospital ended after just a few days.

I was dumbfounded at so rapid a discharge after a suicide attempt! Surely psychosis does not "clear" from the system that quickly? But people, it seems, must cleared from the system.

As he was being discharged from hospital, my son was handed a large black plastic rubbish bag. Inside it were his belongings: his belt, his shoelaces, some clothes, a tube of toothpaste, his wallet. I felt stung with pain on his behalf.

We were told he was being discharged "into the care of the community".

But that is just my husband and me, I exclaimed.

He was also handed a beige official form made of soft cardboard.

Artefact 5: An official form (mostly blank).

There is no information relevant to our son's condition on this card. There is no list of medications. There are no help-line phone numbers or emergency contact details.

On its feint lines where someone could have written useful information, there is just one pencilled annotation – the date and time for an appointment with a psychiatrist made prior to admission to the hospital.

"Try to keep him away from his friends …" said the weary psychiatrist on duty, discharging our son "into the care of the community". *"But it will be no good, he will gravitate back to them"* he added. *"They always do. He must stay at your place. But it is no good. He will be back,"* he sighed. *"They all come back. It's a revolving door here."*

Terkelsen & Larsen (2013) write of patients forced into hospital not as part of some planned, long-term involuntary treatment but rather because of "an immediate crisis" or "desperate situation". "They were exhausted and weary after a long period of drug abuse" and committing them to a locked ward was deemed "crisis-relief". Importantly, such patients as these "were not perceived as dangerous, and they stayed for just a few days" (p. 214).

True to the prediction, after a few days, François was back in hospital, after yet another suicide attempt.

I came to know now that there had been previous hospital admissions too, when, out of concern for his wellbeing, someone had admitted him to hospital. Of these events, we as a family had known nothing.

How could my chronology of knowing be so terribly out of step with the actual events of my son's life? Did others know that I knew so little, about my own son's life?

I also now learned how he had vanished over Easter, the year before. He had been found almost dead in a park by a council worker. François had woken up in a cardiac unit, on life support.

I was grateful I survived, he told us with a wry smile.

Why was it that no one had told us of these earlier events? Perhaps people did not feel free to do so, out of loyalty to François, or perhaps out of obedience to privacy legislation at the time. Would a disloyalty to Australia's privacy laws or a breach of confidence that just let enough of the truth escape, a truth that testified to the depth of his pain or loss, would that have helped any of us at this time? I am certain François had instructed medical professionals and friends not to let us in on what was happening in his life, but why should parents be so locked out of the realities of their adult children's world? We are their next of kin. We are the community when, as mental health patients, they are discharged into our care, after all.

Artefact 6: *In the psychward Part 2* (poem by François, 2006).

This artefact exists in typewritten form and in hand-written form on the cardboard of a tissue box.

IN THE PSYCHWARD, PART 2

By François

She walks the ward with parcels filled
With God-knows-what, she seems fulfilled
To smile and smoke and slowly pace
This crowded yet so empty place.

What could it be that brought her here?
Perhaps she thought her time was near.
Perhaps it is, perhaps it was
A lover who took up their cross

And nailed it with a needle point
Or maybe one too many joints
Or tablets self-prescribed or not
It seems to me a meagre lot

For someone seemingly so calm
At least in here they do no harm
So says the oath, so say we all

So says the sign upon the wall.

And all the while the cigarettes

Pile up like leaves and dust and debts

To banks and friends and dealers too.

Let's hope they are not overdue.

Only once did someone – an allied health worker – contact me about François. She spoke to me for an hour after he saw her, about how I should let my son be independent and how I was hampering his life.

I felt trapped in a double-bind, accused of caring too much and caring too little.

On his next discharge from hospital, I turned to the psychiatrist.

I am going to write to the newspaper about this place… I said.

He put his hand on my arm and looked into my eyes, *Please do!*

The government in our state at that time had a massive campaign to support a football team and to support the racing industry – there was even a minister for racing. Government money had been set aside for use on mental health, but to me there seemed to be little evidence of it being spent in that sector. In frustration and in despair, I wrote the following letter. Alas I have a habit of not posting letters.

Artefact 7: "If my son were a horse" : A letter to the Premier (never posted)

13 April 2006

[In 2004], a [city council] worker found my son lying almost dead in a park, and took him to the [hospital], for which I am eternally grateful. Our son woke up in the cardiac unit relieved to be alive.

In subsequent months we have struggled to get him the help and support he needs to rebuild his life and could have got him appropriate help a lot faster if there were some agency and help given on discharge from the [hospital], outlining the formal and informal avenues of help for young people with mental health issues.

What has saved our son has been the help from non-government and private individuals: his mental-health savvy friends who are not afraid to admit him to hospital when he is unwell again; his brother who having done a Red Cross Mental Health First Aid course, got him help before things went bad; ARAFMI for telling me what's out there; and the newly-opened Aspire Pathway to mental health for suggesting ways to involve his GP.

The [hospital] seems to be able to do nothing but keep young people in a holding pattern until they are well enough to go back out into the community that they are disengaged from.

Psychiatric medicine in total isolation from community support is worth little when the community into which one is discharged for ongoing care and treatment has no coordinated services to serve that vulnerable person. On discharge one would expect some kind of

leaflet or typed list of community services to go to or a list of crisis line phone numbers at the very least. Not just a barren bit of cardboard with a list of phone numbers for diabetes and veterans affairs and the pencilled time of an appointment with a doctor in the distant future.

In the past year thank God we have been lead to find grass-roots support services by sheer perseverance. In the process months of our son's life have been wasted and more damage has been done.

"Please will you write to the papers about all this?" said a psychiatrist to me when I told him some of our previous experiences of the lack of joined-up services here.

Early intervention is something lavished on cute babies, but it seems our youth are expendable in the eyes of policy-makers: federally there is no minister with portfolio responsibilities for youth affairs; and to my mind, youth are discriminated against and feared, ignored and blamed, and left to manage as best they may in a health system that at pays no attention whatsoever to the mental health of youth beyond a certain age.

Listening to my story, a specialist commented to me, "Your son would be OK in this State if he were a horse ..."

Signed ....

4.1.2 "The clinical gaze"

Foucault refers to the "clinical gaze" (sometimes to an "observing gaze") explaining the fairly recent belief in its power expose a hidden truth, a belief which has become a myth, or a metanarrative, one that has allowed for the birth of the clinic and for the way we regard the clinician as our forebears regarded the "seer" (adapted from Shawver, L. 1998. *Notes on reading The Birth of the Clinic*, retrieved 12/14/06 from http://postmoderntherapies.com/foucbc.htm).

We are sitting in a small office with three strangers, psychiatrists complete with clipboard notepads. Only one spoke, all three stare at my husband and me.

Frankly we are puzzled by your son. We cannot tell at this stage if he is schizophrenic or if he has bipolar disorder or schizoaffective disorder – these conditions take two years to diagnose correctly.

Throughout this interview the psychiatrists avoided speaking to our son, or even looking at him. It was as if he were not there. This distresses me and I try to include him in the conversation each time I'm asked a question. I'm at sea anyway: my son is opaque to me.

I used to think the word *opaque* meant transparent, and pictured "opaque" as a word based on opal, that you could gaze into. To this day, I find it hard to come up against the blank meaning of the word. Calling my son "opaque" serves to describe the huge ambivalence I felt towards his medical problems: I both understood them and was completely baffled at the same time. I could feel his discomfort and pain, and at the same time I was stumped as to what it was or what caused it or why.

He has had a psychotic episode, definitely, but we cannot work out why, continued the psychiatrist looking into my eyes for answers, as if I would know.

Please, speak to him. He is sitting right here, I burst out, frustrated at how my son was not being included in this conversation.

I think I have obsessive compulsive disorder, François said. He spoke out the words as if he were spitting out a bitter pill.

At our next meeting together with the medical staff, the atmosphere had completely changed.

Your son is very bright, the psychiatrist beamed at us.

Yes, we know.

We asked him to give us a word beginning with the letter "C" and we had to use a dictionary to confirm the word he gave us even existed, he laughed.

But the really exciting news is that he has diagnosed himself! He is right: he has obsessive compulsive disorder – OCD – and this explains everything.

There was an air in the room of things having been done, accomplished now: he had a diagnosis, a label. The clinical gaze had performed its magic.

As the psychiatrist explained OCD and its manifestations, all I could do was go back over recent times when François had refused to go into the back garden or have anything to do with our dogs, and how he had insisted on repeated occasions, that we all take deworming tablets and how frustrated he'd be when someone in the family had refused to do so. We knew only too well his habit of throwing out any food that was past its use-by-date…

Where's the cinnamon?

Mum! Its use-by date was years ago!

The use-by-date police.

However his OCD was more pervasive than this, we learned now. Obsessive thought patterns played havoc with his own very beautiful maths mind, his music

mind. He'd see patterns everywhere, an ability aided by a photographic memory. Some of his obsessions were easy enough to understand: a keen observer might notice he did not step on the cracks in the sidewalk but the silent computations in his head were invisible. He was constantly scanning the landscape for numbers. Driving, he'd scan car number plates, adding up the numbers to see if they were divisible by 4 – a number he was obsessed with, and the square root of 2.

During ordinary conversations, François would count the number of syllables of words spoken to him as well as the number of syllables of the words he spoke in return. His taciturn manner on social occasions now took on a different meaning.

Artefact 8: "Two letters per syllable" (transcription of a hand-written note, circa 2004).

Two letters per syllable

ve ti na ri an

se cu ri ty

am er ic an

op er at or

in ti ma cy

ce re mo ny

For François, this slide into patterns was hard to counter, yet he would manage his OCD with a determined patience. If it got the better of him, he would come to me

and say, *Please would you mind pandering to my obsession and buy some deworming tablets? I know it is irrational to ask you this, but it will help me cope.* I would joke with François that if I did him this or that favour, he must remember it and pay me one extra visit in the old age home one day. We both found this funny – and easy to agree to, me knowing I would never go to an old age home, he knowing who knows what about his own intentions for his future life. If I complied with his requests, other family members would baulk at taking the tablets, having done so perhaps only two weeks previously. They also wisely suggested that accommodating François' obsessive fear would only work to entrench it – a fact I now acknowledge is borne out by research.

By now, he was seeing a psychiatrist regularly, and he would try hard to practise aversion therapy by going outside to pat the dogs or take them for a walk. However there were subsequent hospital admissions: During a two-month stay in hospital in 2006, I would drive him to medical appointments. I came to see the car was a vehicle for conversation, even if it was also the way of policing our son's freedom in these brief excursions from the locked ward. Sitting in the car, watching seagulls at the beach he talks of how he had thought of studying engineering. But he is looking forward too: *Can you go the Co-op Bookshop and buy me the Dictionary of Philosophy please? I want to learn about Plato and Aristotle. They don't teach us that at university…*

I buy it for him – and take it to him in the psychiatric ward, along with a blue jacket.

Artefact 9: Missing artefact

A letter to a specialist professor about ECT treatment (circa April 2006).

A psychiatrist working on electroconvulsive therapy (ECT) and transcranial magnetic stimulation therapies that target specific areas of the brain advised us that ECT treatment was urgent, because François had such very severe depression. In the mid-2000s, such device-based treatments for affective disorders such as OCD were still relatively rare. Funding at this particular hospital for this treatment was about to be discontinued. An opportunity for François was lost. Ten years later, a randomised control trial by Feng et al. has shown that transcutaneous electrical acupoint stimulation "can be considered as an effective adjunct intervention for OCD" (2016, p. 30).

François said his own informal research had shown which drugs, particularly opioids, ameliorated his OCD symptoms, that he knew the best way to cure himself was through the use of opiates. Covertly, François supplemented his medical prescriptions – antidepressants and antipsychotic medication – with his own concoctions of medications which he ordered online and without our knowledge. Once we discovered this, however we developed a habit of waiting for the postman each day to intercept any parcels from overseas. He avoided marijuana or any illicit drugs that were reputed to bring on psychosis, rationalising that opioids did no harm to his mind. So began his secretive and lethal dance with opioid medications. He began to buy over-the-counter codeine products available at that time as capsules coupled with paracetamol, and in the middle of the night while I slept, he spent hours making a deconcoction to get rid of the paracetamol and avoid kidney damage, he said later.

Soon, however, he realised he needed to cure himself of his growing opiate addiction, and devoted all his energy to getting onto the state's methadone program. This quest was added to his list of obsessions, and he petitioned every health professional he came into contact with to refer him to the methadone program. Only one doctor was registered to supervise the dispensing of methadone at that time in our state. His waiting list impossibly long, and François' chances of getting onto it were low as he was not a heroin addict.

Aware of a rising crisis with my son, I tried to have him admitted to Orygen Youth Health in Victoria where headspace was located. An exception could be made, I was told, to let him travel interstate to Melbourne, but we were cautioned that, as the centre was not a locked facility, there would always be the risk that François could walk out into the streets of Melbourne and vanish (private communication, 2005). We decided we could not risk this, nor could we relocate to Melbourne to support him during treatment. We could not pursue this avenue of help.

Another friend suggested I send our son to the Salvation Army's BRIDGE program.

But he'd meet injecting drug users there… ! I retorted.

So… ? She gave me a long stare.

I did not pursue this avenue of help.

Other friends suggested boot camps in Queensland. I could not imagine him complying with any such model. I did not pursue this avenue of help.

What could I see? I could see an untidy room and a quiet lad, fragile and gentle, hiding from me, shadowy and unwilling to participate, give, talk, hear, listen, or even be. As his anxiety grew worse, I was terrified he would kill himself and sometimes he tried to and I hid all the bits and pieces he could do it with. He ate

minimally. A vegan. And I had to work. And we all had to work. And sometimes we worked long hours and sometimes we were all at home but seldom at a meal table and seldom all together. Often he lay on the couch watching TV. Long days turning into nights and then long nights.

Something happened to time in that time. I could not imagine forward. I could not fast-forward my imaginings to the future and imagine him married with children. I could not imagine next week. I was frozen in today. This battle, with this meal, that trip, this sleeplessness, that worry, this conversation, that task.

Few people knew of our predicament.

Only one person ever contacted me about François.

Your son, he is leading mine astray. He is up to no good. You need to kick him out of home.

Do something. You need to act.

Tough love.

Living on the margins at the other end of the planet, watching my son's mental health deteriorating, I felt helpless.

"Margins" is not the word I seek. Silence is.

"Silence". As in the silence when it snows.

"Isolation". As in the isolation when cut off by deep drifts of snow.

Silence prevailed.

So did fear.

Fear was everywhere but it hid itself well, behind doors closed with swords outside them saying mothers beware.

In my terrible need to know if my son was all right, I arrived at the door of one of his friends. *He's OK. He's asleep*, I was told with a smile.

Mostly, we are edgy with vigilance, aware of our son's fragility. We did not speak. He did not speak. My husband and I take turns at sleeping, waking, watching, listening. Sometimes we are called by his friends to come and bring him home, they are worried something is wrong.

In a dream, I am in one of his friend's cars, driving past our house, and through the window we can see our son in sun, in his room.

His is in a golden cage.

François is safe but living in a golden cage. I try to furnish his room as a bedsitter. Sometimes his friends visit, play pool in the outside room.

The tension in our lives seemed continuous; the fault lines were slowly becoming visible before me; I could sense an earthquake beneath us.

At the end of each day I arrived in my own bed in a muddle of fear. I had a nightmare about impending black clouds rolling towards us in a wave of suffocating fear. Fear had had a good grasp of me but I was stoic about it.

Something feared alongside me, my subconscious that *could* see ahead, that knew something I did not. Or could not. Time blasted on its own way to inevitable events – "events in excess of our frames of reference" (Felman & Laub, 1992, p. 5). I spent long nights sorrowing in advance of my sorrow. We were like pilots on autopilot flying fast through cloud, fearing a train wreck ahead of us in the distance, but never knowing if or when we might encounter it. The future was an impossible thought, placed in front of me like a giant mountain. I was exhausted with worry.

Wilson, Cruickshank, and Lea 2012) write of similar experiences of families who help young rural men with emergent mental health problems, but I had no knowledge of that help nor of any other family carrying the kind of load we carried.

Then: change was in the air.

Would he move to Adelaide as his mentor and a close friend suggested? Or would he go overseas with my husband, on a tour to an arts festival in South Africa and then on to Europe to see relatives?

An overseas trip would give me some relief, my husband suggested, and he began to plan what in by-gone times would have been called *The Grand Tour* – a tradition begun in the mid-seventeenth century. In Goethe's first and at the time most popular work, *The sorrows of young Werther,* the hero attempts to assuage his sorrows with travels of just such a nature, although with tragic consequences. After the publication of *Werther*, many young people in Europe sported blue jackets in imitation of its anti-hero. The Grand Tour has come to represent "the path of healing and enlightenment" (Muncey, 2005, p. 84) and travel can be "vehicle for transformative learning" (Morgan, 2010).

The possibility of an overseas journey with his father, coupled with the chance to participate in an arts festival and air his music at the Grahamstown Festival seemed like sound idea, and soon had an uplifting effect on François, who was given the task of composing the soundtrack for a small movie by my husband, to be screened at the festival. From there, they would fly to Europe, first to Switzerland then to France, and finally to England to visit relatives.

Few knew of my son's predicament. There were almost no people I could confide in apart from a close friend or two, and a psychologist whom I saw regularly– The Hermit. Without his help I would have collapsed in all senses of the word, physically and psychologically.

I told him one day that as a mother I felt as though all I could see of my son were the insurmountable problems, pitfalls and difficulties my son was experiencing,

and that consequently, when I looked at him and his troubled life, it seemed that mountain of problems occupied 98% of what I saw, that there was only 2% of my child left.

Well then, affirm the 2%, The Hermit suggested.

However uneven and exaggerated this ratio might seem, it helped me in conversation with our son to speak to the bright star I remembered. I tried to shift perspectives, to speak to, relate to, dwell on, and above all, trust, the 2%, and to believe in the potential for growth and change.

In retrospect, what our family – and all who were trying to affirm the 2% – so desperately needed was a support network. Our son's "team" comprised our nuclear family, his mentor, and a loyal band of close friends – quite literally a band, which valued the delicate musical compositions that poured out from François' guitar. But we never met as a group to discuss what we could do to help, we were all logistically separated, not elbow-to-elbow. And then there was the uneven quality of my knowledge of what was happening in the problematic realm of the 98%.

I saw The Hermit in the two weeks my son was overseas, a time of living in a blank space, going to work for long hours, making the best of my carer's "down-time". Doing some weekend gardening under the apricot tree, along the fence line I tore out a rose and an old daisy bush. Now the fence seemed to have a toothless grin it displayed bravely to the outside world.

Artefact 10: “LIFE!” (a postcard)

“LIFE!”

This word is all that is printed on the one side of the postcard.

The postcard is now lost, but I have its envelope, complete with a stamp and airmail sticker. It is ready to be posted to Zurich.

It’s dawn but its dark.

Winter.

Your *Winterreise,*

your dangerous journey

begins. But you don’t want to wake.

I tried to wake you but you wouldn’t then you would.

Reluctantly you dress, foot-heavy.

If I knew then what I know now.

But there was the ticket, the passport.

How the camera had stalled.

Your father is ready, cases stuck with orange labels,

your name and number on each piece of luggage.

Long lists of medications, tablets for each day

and a doctor's letter explaining why.

Why you needed all these medicines.

Strong enough to kill a horse they say.

I've never seen anyone prescribed such heavy doses, the young pharmacist had said. *There's something wrong …*

But he doesn't say what. Just that he'd never seen anyone…

The taxi's idling outside.

I am the taxi, fate's unwitting Charon here to ferry you across the Derwent into deeper waters than you've ever been in.

It's dawn but dark.

It's winter here but summer where you're going.

I've bought you coats and bags and clothes and phones and all the usual clutter's jammed and folded. You turn back in your bed to sleep. *No no, wake up* I urge you and you do. You swallow today's pills and pick up the orange-labelled luggage by the handles and follow to the car.

Your brother's silent too.

What if I never see you again.

The thought occurs but does not stay.

What if I were travelling too.

I could but I don't.

And then you're gone, your plane's a red dot blinking in the sky.

Your brother and I, blank like owls, drift home.

Your silence surrounds us everywhere.

Later I find nothing's left behind except a woollen jumper.

I mean to post it to you for Switzerland and so I buy a postcard – LIFE! It says. But I lose it with my wallet.

When it's found, I have another chance to post it to you.

LIFE!

It would reach you in a week – by the time you get to Zurich.

LIFE!

I wrap it in the woollen jumper.

LIFE!

I mean to post it but it will be summer there.

Not cold like here.

And I still did not post it.

LIFE remained at home. Death was waiting ahead of you, in Zurich. On a street corner perhaps, or in a park under a tree. Or near the huge central museum.

* * *

Up the road was a small hall where an earnest group of what I'd call refugees from traditional churches. Their company was a huge comfort to me. I could go to the small services on a Sunday morning and be lost in the singing and praying and feel my earnest heartfelt prayers for my son were getting somewhere.

On three occasions I have to say I believed there to be some inexplicable listening of a different and higher order happening.

The first was when an old priest with the merry air of a retired uncle came to preach. The priest took out his Bible as I told him my story at the end of the service.

He listened and waited with his eyes closed as I kept talking: my son this, my son that. I began to cry. He clapped his Bible closed. *Look* he said. *You need to ask yourself what is the most important thing in your life: God or your son, for where your treasure lies, there will your heart be also. And if your son dies, you will be completely destroyed.* He stood up and went away. I went home feeling blank.

If he dies…

No. This was unimaginable.

On the second occasion a lay reader gave the sermon, a rosy-cheeked young man with a mass of blond curls, said to be a healer. In churches like that, one steps up to the altar and confesses things, and you repent and ask Jesus to fill your heart and you ask for His grace to be sufficient for you. So many parishioners wanted this young man's blessing that he asked everyone to come forward and he prayed for people one by one. When it was my turn, I said nothing. He stood before me with his eyes closed. He was silent for a long while. Then like a steam train at full speed, full of force, his voice thundered *LIFE! LIFE! LIFE! LIFE!* And when he opened his eyes again and looked at mine I could see alarm in his face.

He knew nothing of the card I had meant to send my son. I had still not posted it. It was too late now, they were due in Zurich in a few days.

On the third occasion, a woman prayed with me about our son over the phone. She said she had a vision of Jesus carrying our son, carrying him home, slung over his shoulder like a lamb.

But there's something wrong… she said, *There's something wrong…*

There's something wrong. It seems I often could not see what wise people could see. But then, we are not meant to see the future.

And no one ever believes their child will die.

Overseas now, things are going well. My husband's plan to help our son by taking him on a grand tour is working. He rings or emails me with reports on his wellbeing. Our son has become sociable, happy even. He is "on the program", responsive to people, deeply engaged with other people. The hold of depression and anxiety is weakened. His fears seem to lessen. The paranoia seems to be gone.

Something is working.

* * * * * * *

Ten years later I still struggle to "amalgamate" my own feelings and perceptions with my husband's reports of a complete transformation in François during his travels, when the only "label" he carried was the orange one on his haversack. Perhaps he really was free of oppressive thoughts and worries as he journeyed with his father. At the arts festival, François' musical composition was applauded, and I was told he spent long nights talking movies with the festival director, open, easy … nothing like the guarded, silent person we knew back home.

This new, out-going, carefree young man even participated on stage in a comedy segment, where his contribution – a mighty Arthur Janov-like scream – brought the house down. From this point onward, my husband avers, there was a huge psychological shift in his outlook, behaviour and attitudes.

Only my husband was witness to this change, and back home my elder son and I could not believe my husband's emailed accounts of a happy François. Happy? However we glimpsed happiness in François' final emails. Our elder son had come to me early in the morning, as we got ready to go to university.

Mum, I've just had the best email ever *from François – you should check your mail too.*

But our joy was so very short-lived.

The phone began to ring.

* * * * * * *

On their first day in Europe, in Zurich, François and my husband had explored the Landesmuseum (the Swiss National Museum) and its treasures, each taking a different route through its centuries of treasures. The museum is near Platzspitz Park, once notorious as “Needle Park” but now restored to its former glory after the Swiss Government “medicalised” their heroin problem. In the past two decades, the “social and political context of drug use has substantially changed in Switzerland” (Zufferey, 2009, p. 165) and an article in *The Lancet* at the time of my son’s visit to Zurich explains that drug taking was made “unattractive for young people” in Switzerland (Nordt & Stohler, 2006, p. 1830).

4.1.3 Zurich 5 July, 2006

The vignette below serves to illustrate the careless ease and speed with which a vulnerable young person can slip away into dark places, despite the best efforts of those trying to protect them. It is a reconstruction partly from memory, partly from events I did not witness but imagine, partly from what I was told by others.

A vignette: Zurich 5 July 2006

The heat was unbearable and you took off your jacket and rolled it neatly into your bag, covering the small package. (Would its contents spill? Evaporate in this heat?)

She'd been sitting in the park behind the museum, a very young woman. You could tell that she's a dealer from her eyes – you're good at spotting dealers, there is an air about them, some forlorn dog-gone-ness you pick up like a scent. She puts her arms behind her back and draws forward her woven bag, patterned, with dark green, orange, purple peacock feathers, and a golden clasp. She undoes the clasp. Takes out a small package. An exchange of money takes a second.

You slung your bag over your shoulder and with your step lighter than it had been all morning.

In your bag the small package rocked as you took the train journey with your father in the bright red, new train with hardly any passengers. It drew up at a little village outside Zurich. You walked up the steep hillside with your father, back to the little house on the hillside where you were staying with family friends. You are very out of breath when I speak with you on the phone.

Are you OK? I ask? *You're gasping*!

It's the heat, you say.

That evening you enjoy a barbeque in the garden of family friends where you're staying.

Thunder! Lightning strikes a tree at the forest verge just beyond the garden pond, and half the tree comes crashing down, broken in half. You go inside.

I'll just check my emails and have a rest. Five meters away, your father stands

chatting with your hosts in the garden. Two hours later, a phone rings. It's for you.

Your father tries to wake you ...

Artefact 11: A small package

The contents of this artefact remained hidden in François' haversack until long after the ambulance officers had left. *What has he taken, what has he taken*? they'd kept asking my husband. The package had a label bearing the name of a woman registered for the methadone maintenance treatment program in Zurich. Inside was a small bottle labelled "Methadone", some alcohol swabs, two syringes and needles (one of which had been used) and a leaflet in Swiss German warning about the dangers of overdose.

There were two small marks on your arm.

Lethal, a doctor told me months later.

It's lethal stuff. Make no mistake it is hard to administer methadone, even if you know what you're doing. A "dose" is not predictable.

Always twice, that was your habit.

What can I do? I said,

walking round and round

in the white room

in small circles.

What can I do?

4.2 Part 2: An anatomy of fear

We can only live our lives forward; we can only understand them backwards

– Søren Kierkegaard

In my own chronology of knowing about François' life, I had been lagging at least a year behind in my knowledge of where my son was "at" – such was the nature of my asynchronous knowledge. As I reconstruct from my memory the specific incidents I know about, there are also instances which I do not yet understand – instances of that which-I-shall-be-arriving-at-an-understanding-of, at a future and different end point in this autoethnography.

For the time being it is as if I am looking in a non-reflecting mirror. I strive to "ascribe meanings to life facts, events, or periods that in "real time" might have held different meanings, pointing to the delay, or "postponement," of insight that characterise human existence" (Spector-Mersel, 2014); (Mark Freeman, 2010). How to be? Was it best to be quiet and retreat? To remain silent? Or to write out of a kind of necessity to share my experience? This existential dilemma of positioning myself appropriately continues in the writing of this thesis: how to be in this thesis? What was the "right" way to see what had befallen him? What was the "right" way to honour him? Which way up was right? I was upside down in a world that was now completely upside down.

Two days before our son's funeral, millions of dollars in funding for mental health services were announced: Professor Patrick McGorry's model of headspace would be propagated throughout the country – there would even be a centre in our town. This news arrived in time to be advertised on François' memorial service pew sheet, along with the phone numbers for Kids Helpline and LifeLine, which I included for François' friends.

Behind a façade of coping, fear paralysed me, or rather, awe, in its Biblical meaning of fear and dread. Awe that my life could be so radically transformed, awe that the God I believed in could so terribly intervene in my life and take my son away, awe that I was so weak, awe that I could not control the uncontrollable – that awe possessed me and paralysed me. I understood the root meaning of the word, awful.

* * * * * *

Tidying up recently, I found all the pieces of rope, cord, string, ties, line, twine, even ribbon, that I had hidden away – in the garage, in recesses of the linen cupboard – hidden away from our son. I feared them as much as he feared them, perhaps? Yet he had found a use for a guitar string I had not imagined. He was found in time – in the hospital he had taken himself to, the self-admission he had made to address his problems. I am back there recollecting how the tired psychiatrist had said finding him was Not the kind of way anyone wants to start their Saturday. He had said the words gruffly as if it were my fault, as if he had more sympathy for the young nurse who had rescued our son than for any of us implicated in this tragedy.

The cords, strings, ties, unwind themselves into the drawers and cupboards they belong in. They are filed in the right places again. The tape measure goes back into the sewing box. The kitchen twine goes back with the jam bottles along with red gingham squares of cloth that say “picnic”.

* * *

The world has become reduced to a window. I view it from within. I am completely numb. A numb puzzlement of why. This state lasts for several years, beyond our son’s death, through grief and into the present. I do not recognise my face in the mirror, this cross person is me? I am in a phase of motherhood that has no name. Am I the mother-who-has-a-drug-addicted-child, the mother-who-has-

survived-her-child? The words “widow”, “widower”, “orphan” are clear-cut and familiar terms. “Bereaved parent” seems uncomfortably official. Then I discover another label hovers over our heads.

The term, “suicide survivors” refers to those who survive the one who died and not the survivor of a suicide attempt, and that the voice of those who survive their own suicide attempts is often mute (Peters, Cunningham, Murphy, & Jackson, 2016). François was a suicide survivor for at least one year, having survived several attempts. Reading very recent research by Peters et al. about the feelings that suicide survivors are found to experience, I immediately gained insight into the painful feelings François might have experienced – an extraordinarily shopping list of deep feelings, over and above those brought about by his intermittent psychosis and consequent hospitalisations. The feelings Peters et al. identify are first, the familiar triad of blame, shame and judgment; second, isolation and rejection by friends and community; third, the feeling of being silenced. For the suicide survivor, Peters et al. also list the feeling of bearing the burden of others’ discomfort at hearing the bereaved person’s story.

This last feeling is interesting for my decisions as to what data to omit or include in this thesis. Is it too uncomfortable to include here particular poems of François, for instance? I can justify their inclusion in the spirit of the kind of “heartfelt” research discussed by Martin and Booth, where research “has little to do with subjectivity and objectivity” but everything to do with “caring so much about the quest underway that nothing but the truth of the situation will be tolerated” (2003, p. 4).

The truth of the situation, the verisimilitude of an autoethnography, is often confronting, and most autoethnographies are about catastrophes in people's lives (Tracy, 2013, p. 30).

Writing an autoethnography means writing reflexively, and in so doing, often involves writing about feelings. The "use" of emotions as data is explored by emerald [sic] and Carpenter (2015, p. 747), and by Hubbard et al. (2001). An inevitable part of the reflexivity and self-knowledge which form fundamental elements of qualitative research (Pasque et al., 2012, p. 76) is acknowledging the place of feelings in the researcher's experience. Far from avoiding such topics, autoethnographers are urged to pay attention to "physical feelings, thoughts, and emotions", as these are the very things which expose the autoethnographic truth of "a vulnerable self" that is moved by and may move through cultural interpretation, refracting or resisting such interpretation (Muncey, 2005, p. 70 citing Ellis & Bochner, 2000, p. 7).

4.2.1 Listening and dialogical testimony

My heart is bursting with listening. Maybe that is why I cannot write sometimes, because writing is speaking, and I am trying so hard to listen…

Because I am listening, I cannot stop and think or do or act. This is reasonable: "in the face of testimony … many positions are created for a listener, from paralysis to a flood of awe and fear …" (Felman & Laub, 1992, pp. 72-73; Lather, 1995, p.51).

Taking Felman's reflections on Dori Laub's work, I am both testifier and listener, creating a kind of *dialogical* testimony which becomes a kind of knowledge. The idea of a dialogical testimony helps me to make sense of the silence I am in. Working with silences, as both testifier and listener, I seek "to gain new insights into what *not knowing* means, to grasp the ways in which erasure is itself a part of the functioning of our history" (Felman & Laub, 1992, p. 253, emphasis added).

The position of dialogical testimony and "not knowing" is a way to work with "questions we do not own and do not yet understand, but which summon and beseech us" (,p. xiii). Listening for those questions, listening to testimony, is required to get to the heart of this thesis. In as much that this thesis is a work of testimony, it is bound up in listening. Importantly, part of this listening is listening to feelings – apprehensions.

My own feelings are unavoidably invested in this story: while exploring my son's life retrospectively, it is inevitable that the issue of feelings should emerge, feelings that I have as mother looking back, feelings I felt at the time, and also the feelings that I knew my son had had. Understanding feelings is crucial to my process of meaning-making.

There are also the feelings of my husband and my surviving son to consider. As I write there are feelings of my own that I have to deal with in order to see clearly through to the "facts of the matter" that I am examining in a research context.

As part of my ethics approval for this thesis, for example, I was duty-bound to discuss all these matters surrounding feelings with a university counsellor. While those sessions with the counsellor remain private, an outcome is that dialoguing with him helped me to work with the feelings raised by writing this thesis and importantly, to examine them for their usefulness in meaning-making.

The closed door inside me: not daring to open it.

The closed door at home: not daring to look beyond it.

The closed door at church: not open when I need it.

To help me in my grief when François died, a friend took me to a symphony concert. Gustav Mahler's Symphony no. 9, I learned from the program notes, was written in order to confront the state of "panic fear" and the terrifying loneliness that he experienced when three crushing blows of fate befell him.

The phrase, "panic fear" seems so much more immediate than "panic attack": the component of fear in panic reminds me of the fear I saw in my own son's eyes. Here is the "deep, terrifying loneliness" that Hoffman (2007) believes might be "at the heart of all so-called 'psychiatric' suffering, with the consequent isolation being "the fundamental condition to address" (cited in M. E. Olson, 2015, p. 10).

"Deep, terrifying loneliness" …

"Panic fear" …

"Isolation"…

These words provide me with a profoundly useful way to see my son because the terms resonate with me, and through them, I see my son clearly. They make more sense – as starting points for an understanding, more meaning-making – than the psychiatric words, marooned in capital letters in my mind:

DELUSIONS.

PSYCHOSIS.

EARLY ONSET.

PRODROMAL.

Those words were pasted like labels attached to my son's "case" – labels that did not quite stick. I did not "see" his delusions nor did I have the knowledge to identify his state as "prodromal". Instead I saw "fear" and "helplessness", and I felt

helpless. This encounter with the concept of fear and what I have come to understand as his social isolation proves useful to me.

While I knew then, and still know now, little of the origins of my own son's deep loneliness, angst, or "panic fear", I observed their manifestation and effects on him at the time. It made me, at crucial times, frozen in my very own kind of "panic fear". This made it hard to act differently, or in a helpful way. My own fear was of a lesser order than my son's, but it was fairly pervasive during my son's lifetime. Fear contributed to how I allowed myself to become isolated and lonely (just as he was) in my struggle to help him. Fear in various guises cut me off from being effective.

The journey through grief and subsequently, a reflexive journey through autoethnography, has helped me to arrive at "alternative explanations and views of the world" (Muncey, 2005, p. 84) which in turn have contributed to my understanding of my son and my experience of my son's story. That journey, in both its literal or metaphorical meanings, "represents the path of healing and enlightenment required to move beyond the experience"; it is one that is made up the "patchwork of feelings, experiences, emotions and behaviors that portray a more complete view of ... life". The resulting written account – as data – is useful in constructing a meaningful whole, one that is, hopefully, consistent and coherent and able to "contribute a truth" (Wall, 2006, p. 5).

In the early days of my grief I had felt a nameless feeling, which when I tried to analyse, I described as being "as if every minute were like eating poison" (diary entry, 2007). I had been given this life to live, as one is given a chalice. I had to bear it, to carry it as one would "a bundle of very very sharp things, knife edges, blades, things with sharp, dangerous edges" (diary entry, 2008). These amorphous and sometimes sharp feelings of grief seemed to eat away at me for years and at times I

felt physically ill with grief. I could no longer work, and I retired, three years after my son's death.

One cold winter morning, I rounded on my grief, weary of it. I saw that it consisted largely of fear. Instantly I recalled the opening words of C.S. Lewis's book, *A Grief Observed:* "No one ever told me that grief felt so like fear. I am not afraid, but the sensation is like being afraid" (Lewis, 1961, p. 7).

Here was fear – "panic fear" – again, lurking inside me, bundled up with grief. Alongside it was another ordinary-seeming feeling, a simple one called shame. How often had I felt a kind of unwilling shame in relation to what had befallen our family?

It was then that I realised with a pang like the chime of a Macintosh computer starting up, the depth of my own son's feelings of fear, and especially, shame.

4.2.2 Meeting Shamus once again

Meeting the shadow of Shamus once again lead me towards an understanding of something of the shunning my son had experienced in the last few years of his life. This feeling of shame, sometimes on behalf of myself, sometimes on behalf of my son, overwhelmed what remained of my inner feelings of fear: all sense of fear vanished – and the feeling of pain in my stomach vanished too. My grief had been tamed, it had become manageable. Not vanquished, but rendered manageable. A feeling of grief remained, but it was now a clear-cut emotion. It was simply grief, unclouded by fear.

However the feeling of shame persisted. In the figure of Shamus, the shadowy fear-driven spectre of shame my son had invented in a psychotherapy session towards the end, I saw personified not only shame, but also stigma, and silence/silencing – the kind of silence that surrounds taboo topics such as those addressed in my son's story – depression, mental illness, suicidality, substance use, dual diagnosis, psychosis.

When my son died, a friend suggested I buy a new address book. *People will drop you,* she said in a matter-of-fact tone. In a small town like mine, to step out into the world is to step onto a very small stage and the process of othering can be painfully obvious. Sometimes the unfriending I have experienced has been a sudden shock. It is as if I am …

And that is what I do not know. In this feeling of being shunned, I experience the becoming of stranger, as it dawns on me that I might be perceived to be a parent responsible in some way for her son's death?

Whether or not these thoughts had any foundation in truth, the process of being made to feel *other* was happening to me, as gradually I turned from friend to stranger in some contexts. Shunning is a way of societal punishment well described in Nathaniel Hawthorne's classic novel, *The Scarlet Letter.* While society might dress the other in the invisible garment woven of societal gossip and hearsay, that garment is normally composed of old news and past facts now superseded by a new reality – but sadly the old attitude prevails.

Stigma, like social distancing achieves no therapeutic purpose. Instead, it can compound feelings of shame. In the wake of this thrusting of judgment upon someone afflicted by mental illness – and upon their families – all I can think of now is the word "loneliness". The powerlessness of the one shunned is exemplified in their silencing. There is no one to speak back to, no one to defend a case against. No one sets out to become an addict. Knowing the shunning will happen and is happening, a young person shunned complies, is complicit with, the silencing. Is it any surprise young people sometimes slip back into old habits, into bad company, if only to avoid the loneliness?

While this thesis does not delve into the issue of my son's friendships and peer relationships, some degree of loss of friendship groups was apparent to me as he battled his mental illness and addiction problems.

In our small community, the process of connecting, as opposed to the process of othering, becomes clear-cut in relationships with those involved in drug-related issues. Connecting with people involved in difficult issues seems to be too hard for some people, a difficulty or resistance that bears the hallmarks of othering – *"*others of similarity, others of difference" (Chang, 2008, p. 133). Aware that this shunning is sometimes done with an intent to help those thought to be "doing the wrong thing", I turned to the literature to see how young people so rejected are affected, to learn that cures lie in the opposite direction to shaming and shunning, which not only exacerbate the very social isolation that is symptomatic of problems (R. E. Hoffman, 2007), they also entrench barriers to help-seeking (Clement et al., 2015). We might just as well exhort someone with depression to "pull their socks up" and get over it.

In his last year I arranged a mentorship for François. I have since come to think of this period of mentoring as a way of filling the gap left by not attending university – as a kind of home-schooling for university-aged youth. "J" was decades older than François, and proved to be a mentor who could feed François' intellect in a way that brought him out of the fogginess that his psychiatric medicine seemed to produce. "J" would visit our home for a couple of hours a week of sustained rigorous conversation. They would both read a novel in advance of their meeting and discuss it in depth in the course of an afternoon. François would stay up all night finishing a novel, say by Umberto Eco or J. M. Coetzee, to discuss with his mentor the next day. These conversations – quite literally about "life, the universe, and everything" – were ostensibly centred around a literary work or a movie, but they free-ranged into

philosophy and religion, and also into other issues François would have found hard to talk with us about. Despite their age difference, they shared a keen intellect and sense of humour. Occasionally their discussions would spill over into animated discussions with other family members, and we would catch glimpses of the "old" François once again. Sometimes their conversation would come to a halt if I walked through the living room to the kitchen, and resume once I had closed the door again.

François was deeply engaged in the studies they undertook together and this was one of the few times in the week I could really be sure my son was happy. I knew from my time in youth studies how important mentoring relationships could be for young people. In 2000, the literature focusing on mentorships and underachieving gifted young men was "almost nonexistent" (Hebert & Olenchak, 2000). The benefits of mentorships for young people with mental health problems is outlined in several studies (DeWit, 2016; Jivanjee et al., 2009).

Chapter 5

An analysis of silence

5.1 Part 1: Working with silence

> What remains, the note on which the work dies away … is the final evanescent sound, slowly fading away on a pianissimo fermata. Then nothing – silence and night. But the note which continues to oscillate in the silence, a sound which no longer exists and which only the soul can still imagine hearing, that sound is the echo of our grief, while yet portending the end of that grief, transforming its meaning and standing out as a light in the darkness. (Rosman, 2009).

In the process of creating this product called "autoethnography" it is as if my own life and my son's have met like train tracks in this scholarly account. The parallel lines that were previously the tracks of our individual lives, moving through time in my asynchronous "Chronology of knowing", while my son's life moved along ways not always known to me in his Everyman journey, now converge at the event horizon that is my son's death: the ultimate vanishing point, surely.

The previous chapter focused on the essential aspects of my experience of my son's life leading up to his death. In this chapter, the autoethnography continues with

my experience of my son's death, presenting the data as well as analysis and interpretation. Here I explore the role of metaphor and image in qualitative data analysis, and the use of certain kinds of qualitative data in a scholarly account. I will be relying on a method described by Lather where I construct a story layer and overlay it with another layer of interpretation and analysis – a layering which helps avoid telling a story in "tired, old ways" (Lather, 1995, p. 48). In this layering, I move both forward and backward not only in time, but in my *verstehn.*

Lather's method allows me to move the text "toward a multilayered weaving of method, the politics of interpretation, data, analysis – all embedded in the tale" (Lather, 1995). Her method allows the story to "fold" both backward and forward, in a movement likened to the way an angel in a Paul Klee painting is blown forwards into the future while looking backwards with horror at the debris of the twentieth century – Felman and Laub's explanation of the "angel of history" – an observer angel, whose eyes, widened with terror, see what cannot be halted. The ethnographer/historian "becomes its powerless object" (Felman & Laub, 1992, p. 118).

In this state of powerlessness, I am at a remove now, 10 years later, observing.

I am looking down from Mt Hindsight where I can see the train of our lives blasting onwards towards the train wreck that lay ahead. The train is blasting through the patchwork quilt of country that is Youthland, where story and knowledge live side by side. There are tracks through this countryside, train tracks and way-stations, signal stations green and red.

I am at one of the signal stations now. It's red but I don't see it. *There's no yellow signal for a train,* my grandson points out. Trains can't proceed with caution. Now, the train wreck has happened. All lines converge, a vanishing point is reached

and I have arrived at yet another starting point for discovering more about my son's life, using the fractal patterning of autoethnographic research.

I look around for the words to come, to the spines of the books and journals around me – books I had carefully summarised years before at the Clearinghouse, but how can I take that knowledge "home", and make it work in my research, just as I had tried to make them work in my son's life?

Youth & Society, the journal.

Youth and society the book.

Rob White's *Youth subcultures in Australia*.

Ani Wierenga's *Young people making a life.*

Richard Eckersley's *Well and good.*

NDARC's *Social determinants of drug use in Australia*.

Issue after issue of the *Journal of Early Adolescence* and *Youth studies Australia.* Volume after volume fill my shelves.

How can I activate them, fire up the engines of their knowledge? How can I make *this* work, this "retrospectively speaking"? In my working life, I was familiar with the problems of translating research into practice; now it seems I must translate a kind of practice into research, transmute my own experience.

Telling my son's story makes me feel I am transmitting something, like a lightning rod, standing here giving off sparks: a spark of anger here, the spark of the dying embers of tragedy there – some kind of Cassandra saying look at my story and be warned! I hear bits and pieces of memory, I am "overwhelmed by occurrences that have not settled into understanding or remembrance … events in excess of our frames of reference" (Felman & Laub, 1992, p. 5).

My research goes round in circles. My dilemma is both what *cannot* be written and what *should* not be written. What permission do I have to use my own son's story as data? With this question I meet again the proverbial "Elephant in the Room" that asks all the questions I am never asked by others:

Anne! How can you use your son and his story as data?

How can you make your son's story into a product?

Aren't you exploiting him?

Why do you want to tell his story? To memorialise his pain? To make yourself feel better?

Ethically, can you tell your son's story?

Which part of his story will you tell?

These are inhibiting and confining questions precisely because they are unvoiced.

The Elephant in the Room is the *un*addressable other. It is an othering device. Like my son I am othered – by my story of my experience of his drug taking, risk taking, his overdose and his death. I can do nothing about this othering. Each time othering occurs, I buckle into a kind of acceptance: this is how our society addresses, or fails to address, the uncomfortable truths about the lives of some young people.

It is a similar silence to that offered in the face of grief. More often though I think of this kind of silence as being simply a distaste for uncomfortable subject matter, or taboo topics.

A kindly professor had warned me not to undertake this research: *You would not want to write this story. It might be published one day and sit on a shelf, and your family … Well, they might read it….*

She stopped there. I was puzzled. Our family is not ashamed of this story. My researcher's curiosity was piqued: what was it about grief, mental health issues that was so mixed up with shame that she should feel so strongly that my story should remain untold? Perhaps I was insensitive, too inured to the stories of youth from my everyday work at the Clearinghouse to regard issues of mental health and drug use in the same way most other people do: as matters to be hidden from view?

Perhaps she was warning me about "courtesy stigma" – a term coined by Goffman (1963) to describe the kind of prejudice and discrimination that is extended to people who are linked in any way to a person with "the stigmatized mark"– in my case, the stigma which can attach itself to the relatives of those with mental health problems. Young people are particularly likely to receive this kind of labelling if they are mentally ill or misuse drugs (Corrigan & Miller, 2009; Hinshaw, 2005).

The issue of stigma is an inhibition to undertaking this kind of research, but I persist, in the knowledge that, with difficult stories, the "absence of an empathic listener, or more radically, the absence of an addressable other, an other who can hear the anguish of one's memories and thus affirm and recognise their realness, annihilates the story" (Felman & Laub, 1992, p. 68).

I tell the Elephant in the Room my thesis is not and cannot be a catharsis: *There is no memorializing here. I am writing towards a question and towards a discussion of a question: what can we learn from my son's story about better ways to support gifted young men whose lives fall apart? There is simply getting the writing done, and then seeing what exemplars and vignettes, leitmotifs and threads of meaning can be used for an analysis.*

Yet I ask myself, *Am I respectful, ethical?* I try to be.

Am I telling his story for a purpose? Yes. So others might be saved, a part of me answers heroically – after all, "Mother is always right" …

But *am* I right? And am I making my son's story into a product? I fall back on saying that I am making "culturally meaningful explanations" (Chang, 2008, p. 126).

I tell the Elephant in the Room that it would be more relevant for me to be asking my son all these questions.

I address his absence.

My son is not there.

It is useless sitting waiting.

The sky will not open and show him to me.

The sky wheels by in its enormity.

My son is not there.

The flocks of bright rosellas sweep past, saluting us.

Plovers dive.

At home it is as if we are waiting.

For the door to open, for the key in the lock.

For the sound of his footsteps.

For him to return.

5.1.1 Regarding memory work

Memory work is sometimes categorised as a transgressive form of data, and it is important that I am transparent about its use on the few occasions where it has contributed to my particular process of meaning-making: dream voices – and images – have, and *do* affect and influence my views of the data that I study. A sentimental action places memory on the same shelf as a family photograph, but a research action

takes memory, like a photograph, off the shelf again and "frames" it for meaning-making contexts.

It is pertinent to note that Chase's description of memory's role in meaning-making changed in evolving editions of the *SAGE Handbook of Qualitative Inquiry,* from a past tense to a present tense activity, and that she omitted from her earlier definition the words "past" and "retrospective". In this autoethnography, memory of my son, whether in my waking or my dreaming mind, involves a present tense hearing of his voice ring in my ears – as real as the voice of any other person alive whom I might "interview" for my data.

As if in answer, in a dream my son speaks to me, although what he says is, *I thought you were going to* write *about me, not study.* This too I transcribe, though in the Christian religion, there are prohibitions against speaking with the dead. *Well, there are none about the dead speaking to the living,* I argue with my God …

My recollection of my son's words, whether spoken in his life or in my memory or in dream form, is present, though he is not present in the way an interviewee is present. So too he is at the centre of this account, in a way the writer John Berger best describes:

> All stories are discontinuous and are based on a tacit agreement about what is not said, about what connects the discontinuities. The question then arises: who makes this agreement and with whom? One is tempted to reply: the teller and the listener. Yet neither the teller nor the listener is at the centre of the story: they are at its periphery. Those whom the story is *about* are at the centre. It is between their attributes and actions and reactions that the unstated connections are being made. (J. Berger & Mohr, 1982, p. 285, emphasis added).

5.1.2 The use of metaphor and symbol in meaning-making

As a further aspect of transparency, it is important to stress that I am a poet and believe that images – and especially symbols – are a powerful means to work with material that is not yet fully known to the self, material that is in the state of "becoming known". In this regard, I have come to respect the coming of a symbol, when it does, as something that will unfold its "meaning" in time, unforced, unhurried. Working with the particular and often very specific images and symbols that arise when writing qualitative research, looking at them can be a way of allowing an understanding to emerge from a non-verbal space into the light of everyday consciousness – and that working with them is a way to grow towards an understanding.

In the earlier years of my life, prior to emigration, it had been the symbol of an hourglass that came to represent to me the urgency of making decisions to leave our country. When I had begun this research higher degree, it had been the symbol of a grail-like bowl. Something already emptied, yet capable of being filled…

Was it a metaphor for an abandoned quest? I had held it in mind, grateful for its presence as I wrote. I had trusted I would uncover its meaning for my work some day. I would then polish it just as I had polished a Swiss cowbell that my father had once brought home from Zurich.

As my research got under way, I thought of it as a quest for understanding, a journey that would explain "everything": why things turned out as they did. Interpretively this is difficult and contentious material to incorporate in a thesis. Perhaps it is too much of a stretch to include among my data not only memory work, a contested form of data, but also dream work, and the use of symbolic imagery. However this is autoethnography, and this too is my lived experience: yet another vivid dream of the grail-like bowl, serendipitously on the very day a letter from our

son's mentor arrived, telling me how he had learned more from François than he had ever been able to impart in return. The letter in my hands told me how deeply he respected our son's integrity and intellect, how much he missed their conversations. This very welcome and affirming letter arrived at the very time I had received some other, challenging news from one of our son's friends. The dream and the letter seemed to give me permission to move ahead with interpreting my son's story, allowing me to fearlessly probe my story for meaning: to analyse, to mine for meaning.

This feeling of permission was deeply embedded in the dream's symbolism: the familiar dream-image bowl was set out on the ground at the centre of a forest clearing. It caught the light from every angle on its slightly tarnished sheen. It was more generously proportioned in its roundness than I had imagined years earlier when I had first glimpsed it in the forest undergrowth. It had been lovingly burnished, and hollowed out, enlarged – by our son's mentor!

The finished gleaming bowl was his symbolic gift to me. In the way of dreams, I noticed now that the bowl in the forest clearing was at the centre of an empty room, whose walls had been unfolded outwards, so that the bowl in the centre of an empty room could be seen, observed.

So that it could be … studied!

The symbol had opened itself out.

I realised, even as I held the mentor's letter in my hands: *I am being given permission: permission to look inside, and to explore its meaning.*

That feeling of being given permission is important for me as a researcher, as it left me believing that I am not trespassing on my son's memory nor exploiting his story. Dare I say the feeling of permission was greater than that accorded me by

formal ethics approval? I *felt* free now. To analyse, probe, mine for meaning. I *can* do this research on my own son.

Writing into the unknown, my words begin to fly.

Now, I am a miner cutting a shaft down through to the past. What do I mine? A buried grief that was mourning long before my son actually died?

Holding the torch-light looking down the shaft to the mine's innards is a woman I barely recognise. She is me, but 10 years younger, still strong, and to a great degree, carefree even at the worst times of François' illness. I write of her in the third person, as she is hardly me anymore. She was holding a torch then, trying to see her way and understand things, and she is holding a torch now, trying to analyse and understand. The torchlight reaches into the "black hole" of data analysis to which Lather refers (1991, p. 194).

It is silent down there. It is helpful, necessary, to explore that place – the "place of the greatest density of silence" (Felman & Laub, 1992, p. 64).

Mining.

Fracturing the data.

The act of analysis and interpretation. Balancing "between fracturing data and connecting data again" (Chang, 2008, p. 128).

Under pressure coal becomes diamond. When rock fissures something is revealed: silver; gold; copper; tin. Heavy metals.

Reassembling facts at odds with the story I had been telling myself for years, accommodating new facts about my son's private life, involves a reassembling of my inner world that takes time to settle. While the result is an enriched picture of a far more complex personality than the son I thought I had known, I discovered he was someone deeply at odds with himself and the world. This becomes true for me too,

undertaking my research: a state of being personally unsettled, of being set at an angle that almost physically upsets one's balance, of being at odds with preconceptions, gradually becomes a familiar state as I work with my memories and with new found data.

Somewhere I read that a poet gives birth to a poem twice: once in recollection and later in the writing of the poem. As I write my thesis this holds true for me; what I recall seems firm enough until it changes alchemically in the actual process of writing. It is not just that what I had thought was a fixed memory is changed when I look at artefacts or diary entries for confirmation and find I need to realign my memory with fact. It is rather that the experience of that change or alteration to memory is often unbidden, and not sought out, and sets me at odds with my own process. This experience of being "at odds" with my own preconceptions happens when information comes to me from out of the blue, or when I stumble on it in the process of writing. I begin to realise this is all part of the "analysis" of my story and my son's story. It is my stumble data (Brinkmann, 2014, p. 723).

As I seek an understanding and strive to make meaning after my son's death, I am involved in the intricate process of recreating events in the absence of all the facts.

The silence there is literal.

Meaning-making is slow.

How do I "make" silence reveal what this research inquiry seeks to reveal, how do I make sense out of my son's anguish, and what might his story mean for other young men in our contemporary society?

There is an opacity to my son's story which resists examination. The silence of those who have died is beyond understanding. Silence surrounds secrets. To work with secrets is to work with silence. Our son only revealed secrets when he was up

against it. Ask him a specific question and you would get one specific answer – truthful, but limited exactly to the question. Ask him something general, like, *Are you feeling depressed today*, and you would get something general in reply: *No more than usual.*

In the silence after my son's death there emerges another kind of knowledge, not related to time, or to my asynchronous knowledge as experienced during his lifetime, but a knowledge that can arise only in the aftermath. As I explore the lacunae of what I do not, and did not, know, I am on a kind of moonscape of uncertainties. There are the "givens" of my data, along with the illuminations from the retrospective meaning-making that arrive – or, arise – as I write the autoethnography.

This meaning-making takes the form of insights which organise themselves as leitmotifs of "silence", "listening", "impossibility", "uncertainty" – leitmotifs that provide other, refracted, understandings of my son's story.

A conventional story exploits the tension between the narrative arc of the plot and the secret that only the author knows – and knows in advance of writing (Kermode, 1980). The author of an autoethnography works with knowledge in a different way – working with what is *not* known in advance and which is learned only through the process of undertaking autoethnography itself. While there might be elements of story deliberately used as exemplars, and while vignettes might be constructed and withheld from the plot until they are needed to reveal the meaning in the data, the autoethnographer is largely writing into the dark, writing towards a knowledge claim, writing "live", as a method of inquiry.

Brinkmann explains what I am about to discover: that just when story breaks down, "stumble data" emerge – data that one stumbles upon during instances of "astonishment, mystery, and breakdowns" in understanding, which arise not from

ignorance, but from illuminations of the data in the research process. The nature of this abductive process is, in Brinkmann's words, "breakdown driven" (Brinkmann, 2014, p. 723) and operating from within my own life, and cumulatively, it will illuminate what is on trial in the research.

In some ways my personal experience in writing this autoethnography is also an account of my engagement with the literature of qualitative research. In the process of writing this autoethnography, in the process of creating "data", and in the process of data analysis, the written text becomes not just "an autoethnography" but almost viscerally, the place where I am textually situated, a place of some "second-order reality" (Bochner, 2012, p. 160). It has become a place where I now live. In Chapter 3, Methodology, the "doing" of critical autoethnography had been presaged as "a processes of becoming" (Holman Jones, 2016, p. 229). At last I understand what Holman Jones means by a "citational approach" being typical of critical autoethnography, as a way of "articulating ideas, feelings, understandings, and calls to action" (p. 234).

My methodological self evolves into a storying self, which, being a reflexive self, must be analytical. But I am side-swiped by "critical instances" that can "truly surprise us" and cause "breakdowns in understanding" (Brinkmann, 2014, p. 724). These instances – Shotter and Katz refer to "arresting", "moving", "living moments" or "poetic moments"(1999) – illuminate what is on trial in the research story.

But sometimes, they simply arise, without my seeking them.

All this I understand – but only later. For now, though, I am poised over an orange archive box, quite unprepared for what I am about to stumble upon.

The archive box.

Orange box.

Pandora's box.

This large box contains my data. I have to face it. For my data. A professor's questioning of my methodology (*What's the difference between a novel about the Bloomsbury group and what you're doing*?) had made me doubt myself and it took a while to recover a sense of courage, a belief that autoethnography could serve my research purposes, and a sense of faith that I could be rigorous while doing it.

In the tearoom, a lecturer says kindly*, Just get into your data.*

I am in our son's bedroom, about to open the large orange memory box. It is the black box of my thesis perhaps. On its lid is a large solarised photograph of François. I have been delaying doing this for weeks, months, years. It is now 12:30 p.m. on 31 March, a few hours before a deadline I set myself for writing about my data collection.

I had a dim recollection of having stored here the few effects François had left behind him, among papers, receipts, documents.

I open the lid. There are so many memories inside that I feel faint. I force myself to sort things into categories. School reports. University documents. Funeral documents. Travel documents. Bank statements. Photographs. I see I have also placed there the religious tracts I'd been sent, and the prayers I had said for him. There are medical oddments but not the blank form I was looking for from a hospital. There must be another box of memorabilia somewhere... I carefully separate the scraps of musical notation and poems he had written from the bills and empty envelopes. There are childhood toys alongside his reading glasses, unused packets of psychiatric medication from the overseas trip, and even a bar of Lindt chocolate.

Here are the official autopsy and toxicology reports in a large plastic envelope. I cannot read them now and set them aside, among the letters from friends, tickets to

theatre performances, a train ticket from Zurich. I find the original draft of his poem about the psychiatric ward, written on the inside of an empty cardboard tissue box.

And here is a rumpled note.

It has been folded many times and is foxed at the corners from wear and tear. My husband recalls finding it our son's haversack at the time of his first known suicide attempt in 2005. After his death a year later, I must have packed it away carefully without reading it properly.

Artefact 12: A note. No date.

If I should die with this in my possession, please know that it wasn't suicide. Stupid and self-inflicted yes, but not intentional. I haven't taken particularly good care of my body or mind lately… Though I've always been reckless, and sometimes downright self-destructive, I don't want to die right now, and I hope no one ever has to read this, if you are then I'm so sorry to have left you like this, you all mean so much to me ...

I pray that if I am no longer alive as you read this, that no one is tempted to take their own life, I'm glad I never did when I felt that way. I've learned that horrendous and monstrous as the problems and injustices of this world are, the only response is to confront them with rationality and goodwill, or else we can only be crushed by them which is the greatest tragedy of all. Frenchy.

The note is not dated. Its tone seems upbeat. The voice of the note, and the note in the voice, is cheerful, childlike even. It makes the reader relax… And immediately I am suspicious: Can I trust this voice? Do I, should I, privilege what this voice tells me?

I read the note again and know he imagined I would be reading it, and I know he wanted/would have wanted, to spare me.

Don't stress, mum.

I go through the Pandora's box once again – and my suspicions are confirmed: I find another version of this note, hastily scribbled, an early draft. It is almost indecipherable.

Comparing the two versions, this note is not a rival account in its wording, but, in the uncertainty of its hand, I sense an urgency and perhaps a passion to sort out his own affairs before… before what?

But for now I must go and visit the grandchildren. I need to compose myself and make myself eat something. Have a shower. Look respectable.

After discovering this note I collapsed for a while.

For quite a long while.

I needed to live with my son's note for long enough to regain my scholarly balance and come to an understanding of it, to get to the heart of the autoethnographic process in this thesis, to work towards an understanding of what befell my son.

I have come to call this note my "stumble data". This is what a "breakdown in understanding" is, Brinkmann explains for me (2014, p. 722) – an "experience of stumbling, which causes a situation … and where inquiry is meant to result in a regaining of one's balance" (p. 724). Repeatedly during the construction of this autoethnography, regaining my balance after encountering "stumble data" such as this, has taken time, yet in the process of retracing my steps, my understanding, my *verstehn* has developed.

These instances and stumblings and the "regaining of one's balance" have coincided with, or resulted in, seismic changes in my approach to how I see my son. A note which on the surface of things could be taken as an indication of suicidal ideation could also be seen as an example of his genuine concern for what would become of his musical compositions and its copyright, as well as his equipment, in the

face of his own acknowledged dangerous life-style, his risk-taking. Most of all it is an indication of his deep concern for the feelings of other people, and his desire to spare others any pain: a desire that we who are left behind should not blame ourselves.

In another sense, the note restores some balance to my view of my son. While I have focused so much on his mental health, the note makes no reference to his own inner angst and suffering, and instead is largely devoted to his music. Do I experience my memory of him and represent him through the lens of mental health, or through the lens of his prodigious musical talent and intellect, or through the lens of drug-taking?

Then: amazingly, he is back! Right here, picking up his guitar, playing one of his ethereal compositions.

Loudly, so beautifully.

Elated, I call out to my husband, *François is back, listen!*

It is ages since I have heard him play like this.

Then, I realise: this is only a dream. Yet the sound of his guitar music is right there, the chords of a strangely familiar melody are in my head. So is the sound of the spring rain outside the window.

I gather up all my thesis files and sit down to the task of meaning-making, the music still playing in my head.

Memory, hindsight, recall, data merge. The sound seems to spread out across the trees to the distant river and the suburbs and hills beyond. Something in my son's music and in his story aches to be heard.

Understanding will come. I keep writing. About his music. His guitar. And as I write the word "guitar", my small desk radio responds with the crescendo of chords at the end of Saint Saens' "organ symphony". The synchronicity of it makes me cry as

I have not cried for years. “Guitar” turns into one of those “explicit metaphors” that “gives the outer data while it argues the inner truth” (Kinzie, 1993, p. 284). “Guitar” reminds me: the one constant thread in his life is his beautiful musical compositions.

François expressed emotion through his guitar as if he were conducting electricity through a Tesla coil – his musical compositions for guitar were entrancing delicate highly strung melodies with a frenetic intensity of sorrow and pleading. He spoke through his music. In answer we applauded. Composing the brief musical score for my husband’s movie right at the end of his had done so much to help draw him out, and gave him the chance to feel a sense of purpose and accomplishment, and to be applauded for them. He was using his gifts and talents, and using them in a public way.

Why does this dream appear here in a research report, and how do I explain to the reader its power over my research process?

The dream came at a point when my methodological *understandings* of what I was doing in this thesis were mature, but my *writing* was not commensurate with those aims: I had felt stuck and stale. I was battling with my positionality, and finding autoethnography a gruelling process: how to keep the focus on the object of my study while using subjective means to study that object? It did not make sense. Had I let too much time lapse between taking up the study and writing? Had the time passed for writing about my son? How relevant were my own musings about him to the object of my study and my research question?

Then suddenly it was if my son were right here with me. I cannot interview him as a traditional research thesis would have me do. I had tried inventing a dialogue with him but as a vignette it had not seemed legitimate to include, though it reflected

the tone of our conversations with each other. I filed it away. It had left me perched on a ledge listening, once again, to silence.

Now the silence had been broken: a void was filled, and music had flooded my mind: my son's own distinctive, melodic, hauntingly beautiful and quiet guitar music.

Why was the guitar so pivotal? It was what he reached for, as others reach for a cigarette or mobile phone. It was with him all the time. It embodied something of him that was his quintessential self. How had he managed his overseas journey without his guitar, I wonder now…

The music also loudly drowned out an aspect of my son's life that I had been focused on but not writing about: his drug use.

Write about his drug use, close intimates had urged me. *Don't leave out the drugs.*

Yet I found it very hard to approach the topic of substance (mis)use, and found myself prevaricating about including it in the thesis at all.

Wrestling with an ethical dilemma such as this is typical of the third stage of situatedness which an autoethnographer reaches: textual situatedness. For Neumann and Neumann (2015), a study such as mine takes its researcher through three stages, the first being a kind of autobiographical or as he terms it, "pre-field" situatedness. The next is "field situatedness" – a process of self-situating, accomplished by the previous autoethnographic chapter (Chapter 4). Now I move as an autoethnographer to a more abstract situatedness, which, for Neumann, is the "textual situatedness" of the autoethnography itself. Here, the almost-written, nearly-completed work becomes the source that provides new data and illumines meaning even as the researcher moves from being a collector of data to a producer of data. In this stage of "textual situatedness", a particular focus falls on the ethical dimensions of the study (Neumann

& Neumann, 2015, pp. 798-799). In this regard, I realised I was hesitating about writing about some aspects of my son's life and had been seeing my son as dominated by them. So much of my time as his mother had been spent trying to steer him onto safer paths, away from drug and alcohol use. So much of how I saw my son was through the lens of "straight" mother looking at drug-using child. *Don't. Shouldn't. Mustn't. Can't.* I had taken him to Holyoake, and towards the end, had encouraged him to go to Narcotics Anonymous. He had willingly gone to appointments at local drug rehabilitation services, but always came away dissatisfied.

They don't know as much as I do, he'd mutter, angry.

Now here I was washed sideways by the tidal flood of his music at full bore. Here I am imposing my meaning on his life, and here he is, asserting his meaning, saying, *Remember, I am a musician, not an addict!* His gravestone, after all, testifies to him as "poet, musician". The triumph of his life is how much he leant on music to survive.

5.1.3 A retrospective vignette

A gentle neighbour appears at the fence, pretending an interest in the rosemary bush at the back gate, but casting a nervous glance at our garage, where my son and his friends are practising, drums, guitar, voice, echoing over the Saturday afternoon suburb. I am reminded of her hearing difficulties and how she cannot tolerate loud noises. I tell the boys they will need to practise elsewhere. They move their band equipment with much fuss and bother to a seaside suburb half an hour's drive away, where once again, they face complaints about noise. Eventually they find a hut near the fishing boats, a rickety wooden shelter that directs their sound out to sea. Live music venues face these challenges all the time. How can we better accommodate young people's love of – and need for – music in their lives?

Our house has all its lights on at night. It is as if we are a live unit of electric life, buzzing and thrumming with sound, activity, comings and goings. Radiohead, Pearl Jam, Nirvana, Opeth. I learn the names, facts, genres – heavy metal, thrash – I call it "shoutyshouty music". I take a trip to Melbourne with our sons to hear Radiohead. Another mother sits alongside me*, So glad there is someone else OLD in the audience,* she says. Our sons come with me to hear the Kings College Choir, and to a ballet, to a Philip Glass opera, and respond with enthusiasm. Music was the common thread, a shared love, our background theme. No: vividly in the foreground.

I try to wrestle with creating my data. There is something that will not come to mind, that I must write, that delays. If music was so very much in the foreground then, why did it not come to fruition or bear fruit in my son's life? What did not carry through from desire to action, from intention into practice, from love into livelihood? I had tried to set my son on a course to go to a conservatorium of music, but he broke off that thread very rapidly.

Some of his interests were a flash in the pan, a rapid learning, the mastering of a technique, and then abandonment in favour of the next big thing. We saw the movie, *Chariots of fire*, and for weeks he trained himself, running, timing himself, out of breath, joyful. Then it was cricket, every night on the oval, batting, bowling. Then soccer. Then art. Then music. Music stayed.

At the time he died he had two electric guitars, a battery of effects pedals, a mixing desk, an electronic keyboard and an advanced sound card for his computer, on which he crafted the movie soundtrack highly acclaimed at the South film festival just four days before his death. The last photograph taken at home has him sitting working on this composition, reaching out to adjust the dials on a speaker.

* * * * * * *

His room seems bare. The morning sunlight casts shadows from the window-frame onto the bedcover where one of his guitars lies at cross-angles. I notice how François has given so much of himself away before he died – as many people do when suffering from suicidal ideation. A bedside lamp, a Christmas gift from me some years before, is gone.

Later, we move the guitar from his bed to the outside room, where a large poster for Radiohead looks down from the wall. Another guitar is given to his brother. There it stays. Still later, our little grandson's on the sofa, playing it carefully, as a special treat.

5.2 Part 2: Interpreting my son through a foreign language

In an essay, *On the feeling of immortality in youth,* the eighteenth century literary critic William Hazlitt wrote that "no young man believes he will ever die". Clearly, at the young age of 21, our son *had* believed he would die, for here is his note. Perhaps what he had written is a will, in which he imagined a future where we would need to respond to his absence.

This note is more about life than death, and I have come to call it an "anti-suicide note". Yet writing this now I find myself stuck: I am at a tension point where data and theory do not fit together: My son had suicidal ideation, yet in this note he avers he does not believe in suicide. His death would seem not to have been a suicide, but an accident – or was it? I remained suspended on this tension point a long time. Interpretation, I read in Frank's (2010) *Letting stories breathe,* cannot be rushed.

One day I showed his note to a close friend. After studying it for a while, she turned to me, brandishing the note.

You realise this means you are off the hook? she says.

What do you mean, "off the hook"? I ask.

Well. It means you are not to blame – and that you can't be to blame.

Me …? To blame …? The idea is a shock to me. I had never considered myself guilty. I am left strangely confused about an exoneration I had not sought in the first place.

Most people look at the parents when something like this happens, she explains.

Something like this… Is this, was this, how people were perceiving me/us? I had completely failed to see myself in that light. I had not felt as if I were the object

of speculation or condemnation. Perhaps in the midst of the turmoil of simply trying to cope I had been blind to the opprobrium of others.

During my research I found my friend's explanation to be borne out by Hinshaw (2005, p. 724) who describes the silence and distancing society accords to families with a mental disturbance in their midst was commonplace for much of the past century, and persists in some social relationships today, where parents are often blamed for the mental illness of their children.

Seikkula and Olson (2003) point out that the prevailing psycho-educational family systems approach to psychiatric care, in our Western culture, normally places the cause of psychosis at the foot of the family, and it is as if backs are turned on the family. Therapy for the client is centred on repairing the family *structure,* often seen to be the cause of the client's problems (Seikkula & Olson, 2003, pp. 405, 506).

I had been aware of a supercilious attitude at times in professional or service contexts, something that went beyond a personal manner and realise now it might have been a crude form of apportioning blame. In the heat of our battle as a family I believe we had all been too shell-shocked to pay much attention to how some were treating us. We ourselves were not the "object of therapeutic action" and were largely left out of the therapeutic process. I saw a psychotherapist at the time of my son's death, who had helped me as an individual, but not as any part of our "family system". Psychologists and psychiatrists who treated our son did not see any other family members.

By contrast, in the pioneering Finnish "Open Dialogue" treatment method for psychiatric crises described by Seikkula and Olson (2003, pp. 406-407) both the family and the psychotic patient are involved as competent partners; the focus of treatment meetings moves away from debate about the family structure and towards

ways of building dialogue between people. There is “a constellation”, an “observing system” (p. 407) that is not impatient to get answers or to get diagnoses. A kind of “slow psychiatry”? Where I had been continually asking myself, *what can I do, what can I do,* wanting action even while I knew instinctively that action, solution, cures, were impossible in the current circumstances, Open Dialogue by contrast is characterised by its tolerance of uncertainty. It does not seek to impatiently answer the *What must I do?* refrain. Instead, it follows Martin Buber’s “all real living is meeting” (Buber, 1970) (Friedman, 2002, p. 33) and the German poet Rilke’s advice: *Live your way into the answer.* Writing this now (and living my way into the answer) I learn about the “mystery of the not-yet-said” which lies at the heart of the Open Dialogue technique of dealing with psychosis (M. E. Olson, 2015, p. 6).

5.2.1 The finding

Here,
leafing through stone-quiet papers,
I freeze in the 8 am birdsong morning.
No fog-horn traffic noise or school-song children today,
just daffodils
pinned to spiked leaves
and sea light, far away.[2]

The process of interpreting my son's death begins and ends with the documents described below, and yet it also continues in our own beings, as it were, in an ongoing way, as we piece together a story of how his life had taken on the shape it had, and what the meaning of his life held for we who survive.

For some years I had avoided revisiting this particular data in the Pandora's box that contained the mysteries about our son.

The territory is not quite as difficult as I had imagined it would be. This is partly because of the respectful language used in the Swiss-German documents and the careful translation we were given.

The documents had seemed to take forever to arrive from Switzerland. My knowledge of German is literary – I could not accurately translate the scientific "medico-legal" reports when they eventually arrived.

[2] Poem by the author published in *Poetry Matters,* July 2016.

Artefact 13: A4 documents in German dated 25 July 2006

Universität Zurich

Institut für Rechtsmedizin

Forensische Chemie / Toxikologie …

To fully understand these reports, we had to pay a translator to interpret what turned out to be two official documents: an autopsy and a toxicology report.

It would be another two months before we had an English translation in our hands. In this period of waiting to know these "facts", ones we could literally "read", we were impatient. We wanted so very much to know what these reports might reveal to us about how our son had died. Had he taken other substances besides the methadone, which had been so carefully hidden in his haversack it was only found hours after his death? Was his death an accident or intentional, would the reports show he had he deliberately swallowed a cocktail of drugs in a return of his suicidality?

In the end, what we read still left some doubts. The official documents began by listing our son's death as an "unusual death". "Within the confines of a drug-related death, which may have been intentional (suicide) or the result of an unintentional drug overdose (accident), the mode of death cannot [be] determined with certainty."

In these carefully written documents, one small phrase shone out, revealing an aspect of our son's life critical to my understanding of our son. It pointed towards the inner pain he endured. It was a pain of which we had little knowledge, now revealed as if photographically in the phrase, "non-directional scars". I stared at the words as if

at a map. The "paled" scars were said to be present on my son's wrist and chest and were noted as indicative of "tentamen suicidii". This gentle-sounding Latin phrase means suicide attempts.

"Tentamen" is so easily misheard and misspelt as "testament". For years it has been the reference to those scars, and not the factual chemical analyses, which have stayed with me.

How can it be that this report in a foreign language, written by people I will never meet, would reveal to me the full meaning of my son's anguish in these telling scars? The testament of scars covered up so well for years now unravelled; I never knew about their presence. "Self-harm" was not a term I had placed in the Pandora's box of puzzlements about our son. It was not a phrase used by the Swiss report's authors. With a kind of even-handed justice it held up the two words, *intentional,* or *accidental.* We could interpret our son's death either way.

The truth and plain-speaking of the report was not so much shocking as it was a kind of relief: here was truth, of a kind – a kind of truth we were given, at long last, for the report vindicated my husband's view that the trip had been working wonders with our son's mental health. The report was explicit in its exclusion of any use of cocaine, cannabis, amphetamines, or barbiturates in the 24 hours before his death with "a high degree of confidence". In addition, alcohol was not detected, nor was morphine. From a toxicological point of view, the presence of codeine was detected (he had apparently self-medicated his fear of flying with a bottle of codeine-based cough-syrup) but this "was not considered to be of significance". The report concluded that François had died from the "effects of methadone poisoning" and that one of his prescribed medicines (Valium) "may have played an additional, but secondary, role".

These objective, thorough documents were written in a tone that was not coldly clinical, but painstakingly explanatory, couched in clear language that aimed at understanding, without scientific bluster. There was not one word that smacked of judgmentalism. This accorded with my husband's experience of the compassion with which he had been treated by ambulance officers, police, the investigating doctor, and all Swiss officialdom involved at the time of our son's death. Overdose deaths are common in Zurich, and a compassionate approach seems to have been instilled into the training of all organisations involved in treating people involved in such circumstances.

5.3 Part 3: Psychosis speaks an impossible language

A phrase, whose source I have lost – "psychosis speaks an impossible language" – seers itself into my mind and I begin again to "examine my data".

"Psychosis …"

I write the word and stop. I don't want to go there today. I close my thesis files and walk to the kitchen. At the cupboard, looking for chocolate, I find myself instead inspecting the use-by-dates on jars. Things stick.

Your path is not François' path, The Hermit had reminded me. I stick his words onto my computer screen, I veer onto a different track. Sometimes it gets too hard to write.

5.3.1 A missing vocabulary

Piecing our son's story together, I believe his intermittent battles with psychosis had begun long before the symptoms were obvious, symptoms he hid too well under a veneer of a stoic, sometimes haughty silence. Just as he had not mentioned the bullying he had experienced as a child until the damage had been done, he did not mention his psychological pain. A photograph of François at this time shows him standing tall at dusk with his brother in our back garden. He has an intense, sad look in his eyes. The photo is to send overseas to his dying grandmother who had visited once. We lit a candle at the table for her when we received news of her death. I could tell something was not right in the way François' eyes were averted, filled with fear.

With my mother eyes, as a lay person seeing the sorrow in my son at the time of his acute illness, what I could see was fear: I could only identify anguished fear. Sometimes, seeing this fear, I asked myself, how much was fear and how much was simply a kind of fierce shyness – the sort my own father had had? How normal is

shyness in an adolescent? The sorrows of the world often seem to rest on the shoulders of adolescents, especially those with high ethical standards facing the world's hypocrisy and travesties with their fresh eyes. François' response was cynicism and silence.

Fear.

Acute angst.

Existential pain.

I had no other words in my vocabulary to understand my son. I had no other words to use to explain him.

I believe my lack of understanding of my son at this time had more to do with my missing vocabulary: I did not know the language of the mind in which my son now lived, where an impossible language is spoken, with its own terms and definitions known mostly only to the denizens of that world, to the specialists, and sometimes, the patients themselves.

I believe that my son had an acute awareness of his own mental distress and had been trying to find his way to answers.

Maybe I have Tourette's…

I think I need to go to a pain clinic.

I think I have Asperger's. Could you please refer me to a psychiatrist?

Negative, negative, and negative, say all the results. *I think he's developing the perspective of the "passive observer",* I say optimistically to The Hermit, using psychological terminology like a tin-opener to understand the can of worms that my son's OCD has opened.

We can't discharge him until he develops "insight", say the psychiatrists.

François, like me, needed to understand what was to be *latterly* diagnosed as the *early* symptoms after the event as it were, before the actual onset of what was going to become full-blown psychosis a year or two later.

At this point, my retrospective meaning-making in this qualitative research turns out to have a doppelganger in the realm of psychiatry. Just as there is a retrospective quality to this research, there is a retrospective quality to how we come to understand an individual's slide into, and eventual experience of, psychosis.

While "the prodrome" refers to the early stage of any disease, in psychiatry there exists a more specific, and "retrospective concept" – the *psychosis* prodrome – retrospective because it is identified *after* someone has experienced an acute psychosis. The prodrome in this case is the period *preceding* the psychosis "during which symptoms develop and behaviour change is noticed" (Orygen The National Centre of Excellence in Youth Mental Health, 2016, p. 110). The prodrome can therefore be seen as the "early course" of psychotic disorder; while "early psychosis" can occupy a period of "up to five years from first entry into treatment for a psychotic episode" (Orygen The National Centre of Excellence in Youth Mental Health, 2016, p. 21).

My own "meaning-making" had lead me to understand that the stage of latency called the prodromal phase does not reveal itself for what it had been all along until after the event that *is* the prodromal phase has already happened, and only then can it be identified as such by experts *as* the prodromal phase – a classic "catch-22": receiving help during the prodromal phase is crucial.

But how does one receive treatment in time for something so latent, so quiet and subtle, which does not reveal its true colours until later in the piece? I read that "symptoms develop and behaviour change is noticed".

Without intending to cast aspersions on anyone's intelligence I believe that for most parents, psychiatry sometimes speaks an impossible language, using an unnecessarily distancing vocabulary. What psychiatrists see as tell-tale signs of a state portending psychosis or "the psychosis prodrome" is to someone in the parallel universe that parents inhabit, observing the same young person, "surly adolescent who is doggedly silent" and the words, "rebellious" or "antisocial" spring more readily to mind.

I see no reason that only the professionals should know what these "signs" might "signify", and no reason for quarantining the public from a knowledge which might be life-saving. How then do we find ways of enabling the sharing of a common language around mental health issues at the community level, so that there *are* words to use as a tool for understanding and interpreting the signs of mental illness or suicidality before their symptoms escalate?

For me, one key to understanding the early onset of symptoms in my son, the key to recognising as evidence the symptoms that showed he was in a prodromal state, lies in two words. These two words were spoken only once to me in a brief session with the psychiatrists. They are "accidie" and "anhedonia". I glean their full meanings now, 10 years after my son's death, in the course of undertaking this thesis. Knowing their meaning now, I can with hindsight, use them to see clearly as symptoms of mental illness in my son. I needed words to see. *Accidie* and *anhedonia* are handy as a tool for any parent's armoury of understandings.

Originating from the Greek, acedia, meaning, “indifference”, or “apathy” (Toohey, 2011, p. 108), “accidie” has come to mean the kind of “loss of interest in things” that characterises “melancholy”. I know melancholy well, from my mother and her family, with their fey Scottish feelings, but now I write my own definition of accidie:

Diminished motivation.

Diminished as in piano chords.

On a scale all the way from loneliness

to sadness.

Then on into disaffection,

isolation

to aimless uncertainty and doubt.

A loss of connection.

Something is severed.

Beyond heartsore.

Fearfully

alone.

“Anhedonia” was briefly described to me by a psychiatrist treating my son in hospital as a reduced ability to experience pleasure. My first reaction to this explanation was the thought, *How could anyone be expected to experience any kind of pleasure here!*

We cannot discharge him while he still exhibits so many signs of anhedonia.

As we have said before, we cannot determine if your son has schizophrenia, or bipolar disorder, or perhaps schizoaffective disorder.

The intervening blank space between those two sentences, I realise now, contained essential information that I needed as a layperson. Ten years later I fill in the blank for myself. Anhedonia has been extensively studied in major depression and in connection with a large range of neuropsychiatric disorders, such as schizophrenia and psychosis. Anhedonia is an important negative symptom of schizophrenia well as conditions relating to substance use and risky behaviours (Gorwood, 2008).

Next to *anhedonia* and *accidie* I slot the words, *fear,* and *social withdrawal* in the puzzle of understanding my son.

Shyness also comes to mind as I learn that "*social* anhedonia" is closely related to *introversion*, discrete constructs both associated with "decreased positive emotions" and "decreased sociability" that are common in schizophrenia-spectrum personality disorders (E. A. Martin, Cicero, Bailey, Karcher, & Kerns, 2016). The psychiatrist's words about a possible diagnosis of schizophrenia, bipolar disorder, or schizoaffective disorder float back to me. At the time, the word psychosis had been enough to absorb. The lines between some concepts are very thin, as they are in diagnoses. In a major study by Häfner et al. (2005) cited by Orygen The National Centre of Excellence in Youth Mental Health (2016, p. 22) "the prodromes of major depression and schizophrenia" were found to be indistinguishable from each other. A slightly more recent paper by Häfner, Heiden, and Maurer (2008) found that a depressive mood was common to the onset of both schizophrenia and depression, and concluded that depression, rather than being a comorbidity, is an integral part of psychosis.

If my understanding of my son is occurring retrospectively and only after the event, then what I identify now as that knowledge is a knowledge that is only feasible through the kind of understanding that comes from hindsight (Mark Freeman, 2010).

Was it therefore "normal" for me, at the time, to have experienced so many "blanks" in my understanding?

With the right understanding, might I have been able to help avert the waste of talent that proceeded from this blank space of (un)knowing and ignorance I was in?

Because I had no knowledge about what I was looking at, because I did not have any knowledge of "the prodrome", because I did not foresee what a "prodromal phase" might portend, I did not see psychosis coming down the line.

Psychosis!

I had always imagined psychotic people were wild. Thrashing their arms about, flinging themselves uncontrollably in an effort at metaphoric escape. Running barefoot and naked down the highway. But no, our son was still. Calm. Wooden.

Wooden? Ah, now there's a way of describing the meaning of anhedonia!

Given that mental disorders are so prevalent in young people, would a knowledge of these related concepts help parents and teachers to "see" the youth around them who might be suffering and in need of some understanding? Does the knowledge of the prodrome, of the meaning of anhedonia and accidie, have to remain isolated in the realm of "mental health"?

What might it look like for youth mental health if this knowledge were filtered into education settings? Words – a widened vocabulary – can give a voice to what is otherwise an impenetrable silence, not only for the parent or teacher, but also for the young person.

No words … no voice … no agency.

Silence.

All *I* have now is my voice.

5.3.2 The idea of impossibility

Sometimes the idea of impossibility surrounds me, blankets me in silence, especially when I have written myself into a corner, into an impossible space. Sometimes it feels impossible to do my son's story justice, yet equally it is also impossible for me not to try to write it.

The Swiss report had left us with an open finding. A dialogue between me and my husband continues to this day about the nature of our son's death. My husband is adamant that our son's death was accidental, and counters the memory of others including myself that are so clouded by his earlier suicide attempts. My son's crumpled note bears testimony to his own knowledge that his risk-taking was extremely dangerous and liable to be lethal one day.

As evidence, my son's note and my husband's account stand before me. It is impossible to talk to my son to check facts. In his lifetime, it was often impossible to get a response from him, to get him to talk to me. Now here I am, dealing with an impossible language of silence, and trying to use it as my data and analysis.

I escape the tight confines of impossibility by remembering Foucault's saying that in modern psychiatry, there is, now, an absence of a "common language" due to a "broken dialogue" in our talk of mental illness (Foucault, 1988, p. xi). In my experience, both the psychiatrists and my son in his psychosis seemed to speak an impossible language to me. Their language was spoken to me, at me, not with me, not dialogically.

However, during episodes of psychosis, my son spoke in silence. To that space I now travel, back in time.

In the last year of my son's life, I lived in silence, in the midst of what I felt was a puzzled incompetence. I was flying blind, after all, but trying to listen, understand. Yet I felt thwarted. What could have broken this silence I learned only recently, from Mary Olson's paper on the Open Dialogue method. Citing Foucault's words on a common language in psychiatry, she writes that such a "language" can start from "*various chords of resonance: single words, stories, a shared image, a silence, a particular gesture, a situation …"* (Foucault, 1988; M. E. Olson, 2015, p. 3).

Chords of resonance.

I realise we were all skilled, in our family, in our own way, at sharing with François in this odd manner. There *were* chords of resonance between us, not only in the music we shared at that time, echoing through the house – Radiohead. Pearl Jam. Nick Drake. Our chords of resonance echoed in the poolroom, with the loud click of snooker balls. In humour – Bill Hicks. Dr Katz. Spike Milligan.

Living together was not hard. It was not tense, but it was often quiet. Silent. In our family, we had acquired a private pattern of understanding each other, one that was imbued with understatement, irony, humour and a deep respect, but we were not carelessly conversational. To our arsenal of communication strategies we added a pool table in the outside room, to make up for what was lacking in dialogicality. This gave us valuable opportunities for open-ended conversations with François. With everyone working, studying or sleeping at different times it was often only late at night playing pool that we could talk.

Gestures of respectful acknowledgment of each other's presence were shared among us all as we tried hard to reach out to François. Unknowingly we practised then what Open Dialogue suggests now: "attending to key utterances that visibly

touch the speaker and/or listener and suggest inexpressible or unspeakable dilemmas otherwise embodied in behaviors" (M. E. Olson, 2015, p. 3).

This attending, I believe, was also a kind of tolerance for our son's dilemmas – not a tolerance of his substance use or behaviours, but of his dilemmas. That kind of tolerance felt very much like holding the thread long enough to endure, so that we could reach him – in order that "the inexpressible [could] be given a voice" (Seikkula & Olson, 2003, p. 410).

Such dialogism, at the heart of the Open Dialogue therapeutic setting, was absent in the kind of silence we were experiencing in so many other ways at that time, but that was a silence that seemed to come at us from the outside.

In a way I am practising a kind of dialogism now, in the absence of my son, as I try to work towards an understanding of him, giving him a voice in his absence, here on these pages.

It is an uncomfortable space to work in, this snowy silence of absence, overshadowed by the spectre of psychosis.

It seems that the idea of the uncomfortable, of being at the uncomfortable edge, is important as it is at that place of discomfort that understandings and solutions to problems are often made. Musicians such as John Cage who work on the margins – and other outliers at the edges of art practice, seem deliberately to seek out the area of the uncomfortable, and there, at the very edge, create their unique art. They are not afraid of the uncomfortable. "To be creative, you have to go to the margins", states Norwegian psychiatrist Tom Andersen (cited by M. E. Olson, 2015). Working creatively at that uncomfortable edge might equally apply to our research positionings, or to the places we find ourselves in our families.

If we can bear to stay on the uncomfortable edge that is our companioning of those with mental illness, or on the uncomfortable edge in our relationships, something positive will grow.

Chapter 6

Discussion: An "ecology of understanding"

Focusing on the dimensions of an "ecology of understanding", Altheide and Johnson (2011) write that good ethnographies display tacit knowledge through contextual understanding and through accounts that "increase our confidence in the findings, interpretations, and accounts offered" (Altheide & Johnson, 2011, pp. 590-591). It is my task now to increase confidence in *this* account by outlining my understandings of where we are at regarding my research question: *How might a mother's autoethnographic account of her son "falling through the cracks" help us to better understand and support Australian youth experiencing mental illness?*

The preceding autoethnographic chapters described my attempt to make sense of my younger son's life and his death. I began Chapter 1: The Introduction, with MacIntyre's (1981, p. 216) statement that we can only answer the question "What are we to do?" if we can answer the prior question, "Of what story or stories do we find ourselves a part?"

In answer, I believe we are part of two stories. The first, a personal story, a single case, a portrait of a life, is one which does not reach a denouement here, since

it continues to reverberate in my own life, beyond this thesis "end point" (Gergen & Gergen, 1988; Spector-Mersel, 2014). It continues to reverberate due to its impact on the second, a more public story, of which we are all a part. Those two stories, the personal and the public, are the basis of my reflections in this discussion of the issues the autoethnography raises. If autoethnography's refracting lens of the personal is able to shine a light on culture, as claimed in Chapter 3, Methodology, then I believe we in the midst of a story of youth mental health, in a time of policy disarray.

Youth lead precarious lives due to a variety of uncertainties in our society as explained in Chapter 2, the Literature Review. Their needs are complex, especially regarding support during times of mental illness. To ask how contemporary society supports young adults might seem contradictory: surely growing up means learning to be independent of support? Surely enough vestiges of the idealised village that it takes to support a child remain in contemporary society, arguably represented by people like teachers, counsellors, psychologists, sports coaches, mentors, arts workers, youth workers, religious leaders? All these people-of-the-village support youth. However the key problem is that that they do so from services that are often "silo'd" from each other.

Latham (2001) traces the origins of the "silo-based" approach by government to problem-solving to the previous century's segregation of human needs "into a neat set of functions and categories" like education, health, transport, but services arranged "like a set of silos, with no common strategy between government agencies" makes it harder to address "whole-of-life" problems that demand "a whole-of-society solution" (Latham, 2001, p. 255). Mental health policy-makers have to drive policy and practice across multiple silos comprising "all three tiers of Australian government and … multiple jurisdictions" and to engage "public, private and non-government sectors"

simultaneously (Rosenberg & Hickie, 2013, p. 1). They are expected to build bridges across "departments, governments and providers" and across widely differing disciplinary domains. Delivering good co-ordinated care is understandably a major challenge for policy-makers: "a key finding of the *2006 Senate Select Committee of Inquiry into Mental Health* was that policy and "service silos" were "preventing effective care (Australian Senate, 2006, p. 18).

As "critical autoethnography", my study seeks to "open up conversations about how people live" (Ellis & Bochner, 2006, p. 435). Critical theory reveals its influence here with an implied critique of government policy-making and social justice deficits, even if critical theory *per se* was not used intentionally within the research design. The "critical" in critical qualitative inquiry makes me ask, what might be done to effect change in the lives of people like my younger son, lives that indirectly bear the brunt of policy decisions made at the macro level regarding youth mental health? It would seem to be symptomatic of the dysfunctional nature of mental health care in Australia, and of the failure of our silo-based services, that the country has, on the one hand, lead the world in policies and plans to address mental illness, and yet on the other, has failed in the implementation of those policies and plans (Rosenberg & Hickie, 2013, p. 4). Rosenberg and Hickie posit "one recurring reason" that explains the impact of the failure of mental health policy: "the inability of mental health to surmount policy and service silos" (Rosenberg & Hickie, 2013, p. 2).

Young people's lives, with all their uncertainty and existential angst, are deeply rooted in the public domain, where broad policy and societal pressures exert a powerful influence, well beyond the control of young people (Bauman, 2004; Giroux, 2014).

At a deeply personal level, I wonder how my tacit knowledge might have

served me better during my son's life, and why the kind of tacit knowledge I had, drawn from the research knowledge in my office, did not transfer itself easily and allow me to apply that knowledge into my life – to the realm of practice. I was as helpless as any other parent when it came to finding practical help for my son. I have come to see the reason for that failure lies partly in policy settings, rather than in any personal settings. I will now provide a brief comment on just one strand of public policy affecting young Australians' lives: national youth policy.

In 2009, I sat on the national youth policy roundtable that met in Canberra to formulate a national youth policy. Curious about what has become of the 2009 national youth policy, I recently made some inquiries about it. The answers and silences I received speak into the arena of silence that is a constant theme in this thesis.

Artefact 14: Extract from an email on youth policy (private communication, 2 November 2016).

Hi Anne,

Thanks very much for getting in touch with [me] concerning the representation of young people at a federal government level.

Basically, there is not a current youth policy within the federal government. Specifically:

- *We have no federal minister for youth.*
- *There are no regular mechanisms within the federal government for engaging with young people.*
- *There is no independent youth peak advocacy body (AYAC used*

to have this role, but they have lost all their federal government funding and can no longer operate on any regular basis).

- *From 2017, the federal government have cancelled their funding for National Youth Week, a week of events designed to celebrate young people's achievements and community contributions.*

Issues affecting young people may be handled within various other portfolio settings, notably Education, and Social Services. However, we would contend this is not an adequate approach. Not all young people (aged up to 25) are still in the education system, and young people's lives include far more than education. Meanwhile, much of the push in the social services policy space has been to reduce income support available to young people without much of an overall, evidence-based 'vision' for how youth poverty, unemployment or underemployment might be prevented and reduced. Without a designated youth minister, there is also a heightened risk that a government can lose sight of the particular issues faced by young people, and how issues such as health or employment can play out differently for a 20-year-old to, say, a 50-year-old.

I hope all this helps a little,

Best wishes

Without any clear ministerial responsibility for youth at the cabinet level in government, and with responsibility for youth affairs distributed across different portfolios, it seems there is no unified national youth policy in Australia.

How can policy-makers support the youth voice and "investment in resources

for parents and families" and make them priorities (Rickwood, 2011) when there is no national youth policy?

This hole in the fence of policy makes getting unified and coordinated action to address conditions for vulnerable youth, such as the mentally ill, complicated.

My experience in gaining an understanding of my son, and in gaining help for him, is partly an example of how we battle to translate knowledge into practice and how we fail at phronesis – the practical wisdom gained from experience and applied in real life situations (Landman, 2012).

Alternatively, perhaps the very "knowledge" I thought I had was in fact a barrier to "seeing" my own son? Could it be that we can believe we know, but do so in a superficial way which makes us *feel* expert in our own domain of expertise or knowledge, yet not *see* well enough across the neighbouring fences? And are we brave enough to shout across those fences … which are in fact not fences at all, but silos?

Youth services and resources for young people like my son, living in remote areas of Australia, differ in policy from one state jurisdiction to another. These differences influenced the outcome of my son's life in many ways, but describing them was beyond the scope of this thesis. I have been more concerned with intangible problems caused by insufficiencies of our responses to youth – the silences and inaction, "invisible" factors like ignorance, fear, shame and stigma.

One of the many outcomes of writing this thesis is that I have come to understand our son in a new way, especially regarding the extent of his pain, and the role shame, self-stigmatisation and self-shaming played in my son's life. "Shamus", whom he invented as his alter ego during psychotherapy, symbolised his reluctance to disclose his troubles or seek help, both before, during, and after his severe encounters

with mental illness. Shame can be inhibiting and traumatising, as shown in research by Turner et al. (2013), who shed light on the contribution of shame to post-psychotic trauma. These researchers conclude that services should "make admission and inpatient experiences less shaming" (p. 174), which would go some way towards mitigating the depression that is often a consequence of experiencing psychosis (p. 175). Conversations about mental health have to be had out in the open about the specific and often confronting facets of mental illness such as post-psychotic trauma and suicidal ideation.

Researchers have been "slow to turn their attention towards the question of how such stigma associated with mental illness and substance use disorders can be reduced" according to Livingston et al. (2012, p. 40). Their systematic review (already cited in Chapter 2, The Literature review) found that giving training and education programs not only to medical students and professionals but also to police and counsellors, was effective. Such training programs for police significantly reduced police officers' "desire to maintain social distance" from those with substance use disorders (Livingston et al., 2012, p. 40). The need for this training of non-professionals is underlined by Jones and Crossley (2008) who found that one reason feelings of shame were aroused in patients in hospital settings was due to "non-mental health professional' attitudes towards mental health problems" (p. 753) and that "collaborative research" between professionals and service user groups "appears ... to have potential remedial value" (p. 756). My own family's experience bears out these researchers' findings. In Switzerland at the time of our son's death, my husband remarked on how consistently he was treated in a respectful, courteous manner by everyone attending the scene, from ambulance officers to police, and later by counsellors and all other officials and service providers with whom he later had

contact. For my husband, the trauma of dealing with our son's death was hugely mitigated by this non-stigmatising treatment accorded to him. He later learned the Swiss had endeavoured to educate everyone, at all levels, about substance misuse and overdose as a health issue and about the harm of stigmatising judgemental attitudes, and that one result was that, as drug use became a health issue, heroin users for example transitioned rapidly into treatment and recovery programs (private conversation, July 2006).

6.1 Ignorance is not bliss: the issue of suicidality in youth

My son's suicidality is very difficult to unravel and as a mother, extremely painful to explore. Suicidality frightens me on many levels, and I was not forthright about it with my own children as my mother had been with me. François had addressed the subject very frankly in the pivotal note in what I called the Pandora's box of data I examined in Chapter 5, section 5.1.2.

It is unclear what happens beyond the family home that fails to protect vulnerable people from suicidality, in the "chain of well-intentioned approaches to treating psychiatric illness" (De Leo & Sveticic, 2010). On admission to psychiatric wards, patients commonly report feelings of worthlessness, hopelessness, anxiety and depression (Large et al., 2014, p. 119). The fact that psychiatric hospitalisation is frequently described as an adverse experience, and that a number of psychiatric patients attempt suicide in hospital, as our son had done, is a phenomenon that has "received surprisingly little attention" (Large et al., 2014, p. 119). De Leo and Sveticic point out that there is "no convincing evidence that in-patient care prevents suicide", but instead, "paradoxically, both admissions to a psychiatric ward and recent discharge from it have been found to increase risk for suicidal behaviours" (De Leo &

Sveticic, 2010, p. 8). This is a taboo topic that needs further investigation. Ignorance is not bliss, and knowledge of this risk might be helpful to parents however panic-stricken they might be, and however alarming such knowledge might be. Suicidal ideation is seldom addressed as a distinct, as opposed to a comorbid condition, and to see it outside the frame of mental illness might prove helpful to finding new treatment options (private communication, 4 December 2016). Diagnoses and treatments for mental illnesses, such as bipolar disorder, or schizophrenia, are also frequently complicated by suicidality.

In this arena, there is an urgent need for service providers to understand young people's "existential" needs in a holistic way. One suggestion made to me by a professional was that youth-focused services should operate within psychiatric wards, helping to create a therapeutic community. Such a community would be able to better support young people with emerging mental health problems, normalise the experience of being in a psychiatric ward, and educate those working with young people in non-professional roles about their needs and feelings (private conversation, 4 December 2016). Having youth-focused services within hospitals would help destigmatise their treatment, help prevent suicides and help create the opportunity for greater dialogue between the family and the treating medical professionals. Certainly it would avert some of the problems our family experienced, and help overcome the experience of isolation in a time of trouble.

Youth sometimes seek to soothe their existential anxiety too readily with quick fixes yet seeking out "the softly drug", as François' story shows, is to pursue a false hope. *There are no soft drugs,* our elder son had said at his brother's funeral. And it can lead to death. Far better then to do battle with the existential dread that drives us to the softly drug? I still hanker to know, *How might society help mitigate*

the feeling of existential angst in young people?

As for the action that young people themselves might take, Vonnegut speaks these wise words:

> What should young people do with their lives today? Many things, obviously. But the most daring thing is to create stable communities in which the terrible disease of loneliness can be cured. (Kurt Vonnegut, 1974. Commencement address, Hobart and William Smith Colleges.)

6.2 Becoming advocates for youth mental health

While there are calls for advocacy and awareness campaigns, the speaking out that is needed and the courage to speak out that is needed, is undermined not only in policy settings but in fractured research settings too. Very different disciplines, such as medicine and sociology, have the concerns of youth on their agendas, and any improvement for youth wellbeing would seem to require far more interdisciplinary knowledge-sharing than happens at present. This underlines a need for overcoming the barriers between research and policy endeavours, so that *practice-based evidence* can speak to *evidence-based practice* (Staller, 2006). In Fielding's words, in order to build a "cumulative knowledge of the social, we need to synthesize, not fragment, and to talk across borders" (Fielding, 2017, p. 17).

My experience is echoed to some degree but without such tragic consequences by one of the world's experts on youth mental health and a former Australian of the Year, Professor Patrick McGorry AO. Launching a book of poems I wrote in response to losing my son, he told the audience that he himself had very nearly lost one of his own sons in a very similar fashion to François. Here stood a parent, no more immune from what I had suffered than anyone else, and willing to share his story so publicly –

as an advocate for improving youth mental health, as well as a subject expert.

Regarding funding for youth mental health, Professor Patrick McGorry has made the point that if cancer were underfunded to the extent that youth mental health is, or underplayed to the extent that youth suicide is, society would be up in arms. His frequent exhortations to the community to speak out, loudly, about inadequate funding for youth mental health, leaves me wondering: How might ordinary individuals in the community effectively marshal the energy to speak into policy spaces about mental health issues? How do they – how do we – break the silence – around, for example, shame and stigmatisation?

Anne Deveson's (1998) brave work on improving our awareness of schizophrenia is a fine example of the effectiveness of voices speaking from a parent's perspective into policy arenas. Work such as hers allows everyday "working knowledge" or phronesis to link up with research and policy domains.

6.3 Sharing a common language

> As for a common language, there is no such thing; or rather there is no such thing any longer; the constitution of madness as mental illness, at the end of the eighteenth century, affords the evidence of a broken dialogue … and thrusts into oblivion all those stammered, imperfect words without fixed syntax in which the exchange between madness and reason was made. (Foucault, 1988, pp. x-xi).

> A common language can start from various chords of resonance: single words, stories, a shared image, a silence, a particular gesture, a situation. Open Dialogue emphasises attending to key utterances that visibly touch the speaker and/or listener and suggest inexpressible or

unspeakable dilemmas otherwise embodied in behaviors. (M. E. Olson, 2015, p. 3).

In Chapter 4 I described the helpful action of a psychiatric nurse who rushed out to urge us to find a psychologist for our son. She acted purely from listening to his story. Her "gesture" was life-saving at that point leading our son into psychotherapy. In an article on "unknowing" and mental health nurses, Lakeman speaks of the efficacy of those kinds of acts that come from a "position of unknowing", a position which, "when employed mindfully, could be a critical ingredient in fostering therapeutic relationships with otherwise difficult-to-engage people" (2014b).

By contrast, many non-professionals working in mental health are not as well-informed as professionals and experts in the field about the extent of shame and stigma in the young people with whom they have everyday contact. There is also a need to educate others in regular contact with youth – a need recurs in the literature, for example, in Corrigan and Miller (2009), and Livingston et al. (2012), who explain that "landlords, employers, police officers, policy-makers, and primary care physicians" need to know more about stigmatising assumptions about mental health.

6.4 Re-starting a dialogue about mental health?

Much of my concern in this thesis has been centred on conceptual questions about how we unpack words or the terms for concepts to make them real and "live" again. The concept of "mental health" is a case in point. At a certain point in writing this thesis, I found myself almost allergic to the term. "Mental health" began to feel like a bland, meaningless term, over-used like a worn-out blanket. So too the term "wellbeing" began to vanish into a generalisation – into the vague world of "normal" people …

Bridging the gap between our different vocabularies takes time – and it takes a

dialogical approach that is alien to our time-constrained contemporary world. Whatever language we use, a dialogue about these issues is of huge importance and could be healing.

Regarding exclusion, Michel Foucault has pointed to the absence of a common language in psychiatry as being a "formula of social exclusion" (Foucault, 1988, pp. x–xi). An antidote to that exclusion might be found simply in ways of dialogue, in the Bakhtinian sense. Some of the successful therapeutic action for my son consisted not only in dealing out diagnoses and medications – which have their place – but in the respectful, patient silences and pauses in conversations where we held a thread of communion without words – for example, during a game of pool, driving somewhere together. In Chapter 2, The Literature Review, I referred to Lynn Hoffmann's description of "dialogical therapies", and I have mentioned the Open Dialogue model of treating first episode psychosis often, because I believe that it is through dialogue with our son that some answers were found – and through a more dialogical approach, other answers might have been found (M. E. Olson, 2015, p. 3; Seikkula & Olson, 2003).

Open Dialogue sets a stage where people representing different "sectors" in the research/policy/practice realms meet. It is a way of breaking down the silos that define so much of how youth services are structured. Recent Australian reports such as the National Mental Health Commission's National Review of Mental Health Programmes and Services have a similar emphasis on a "person-centred approach" (Hickie, 2015, p. 9), where people are seen as pivotal to any mental health system.

6.5 Supporting vulnerable youth

In a variation of my research question, and given the policy vacuum in youth policy arenas, I ask, how *do* we support young people with mental health problems? I

believe it is vital to persuade policy-makers of Mills' (1959) belief that private troubles *are* public issues. It is also vital to persuade the community that those issues are not just the concern of services and those who work for social justice for young people. They concern us all.

Irrespective of my scholarly position, be that criticalist or interpretvisit, or my leanings towards youth transitions research, or to developmental or cultural approaches, I believe that many young adults are in a precarious situation through structural conditions in our contemporary society – well explained by Giroux (2014) – and even more so, those vulnerable to mental illness.

It has been one of my aims in this thesis to take a broad-brush approach to the research literature and seek to draw it into my account to forge links between research and practice, so that separate realms of ideas might be forced together so their edges meet. One way to do this is through the ordinary and everyday habit of reading. If we read, and reach, beyond the boundaries of our own silos, how much wiser will we be, and how much better able to apply knowledge from one field to another?

6.6 Reflections on a broken dialogue

In many ways, a "broken dialogue" (Foucault, 1988, pp. x-xii) is inevitable when we try to have when we try to speak across paradigms and practices. Yet in those interstices there is a fruitful area of meeting, of discussion.

This thesis has told of spaces we stride over as a society with regard to young people, especially those experiencing mental illness or metaphysical pain. I am aware there is much else that remains to be said. Some of the steps "over something not said" (J. Berger & Mohr, 1982, p. 285) are due to omissions of information that was not my own first-hand experience. This thesis itself is the result of trying to manage the various levels of "life as lived", the "life as experienced" and the "life as told"

(Bruner, 1986, p. 6). This written report has had to be filtered both by the needs of an academic "product" and the needs of meeting university ethics guidelines in order to protect vulnerable people. The autoethnographic chapters traversed a map with many holes in it, emblematic of the gaps in my knowledge, in the youth field, in policy settings.

Autoethnographies can be defined as "case studies that follow the tradition of ethnographic research" (Duncan, 2004, p. 29). My son's story could have been a case study; I could have used case study as "a design frame" (G. Thomas, 2011, p. 512), with autoethnography as one of the methods within it. This study has turned out the other way around, with an autoethnographic design frame and a case study at its heart.

Because an autoethnographic approach predominated and my son is viewed almost exclusively through my eyes, the portrait of my son is limited. However this has not, I hope, reduced the power of his story. He was an eccentric, unique – an outlier. In qualitative research, "[n]egative cases [can] often provide the key to understanding the norm" (Morse, 2015, p. 1215).

The "force of example" is underestimated in research (Flyvbjerg, 2006, p. 228) – as it is in life. At my son's funeral, a young friend of his stood up to say,

We have to change our lives.

I hope that reading this account of my son's life and his death will provoke others to say something similar:

We *have to help change young people's lives* …

6.7 How many stories like mine will it take?

> In the early 1980s, it became obvious that the needs of patients with first-episode psychosis … aged 15-45 years and their families were strikingly different from those with longer term illnesses. Issues

> included grief and pessimism pertaining to diagnosis, exposure to frightening adult institutions and chronic populations, suitability of medication types and dosage, and age appropriateness of psychosocial interventions... (Cotton et al., 2016, p. 1).

Nearly 40 years later, I ask, is my story so very different? Who cares that the story of my son's first-episode psychosis and his family's consequent "grief and pessimism pertaining to diagnosis", our son's "exposure to frightening adult institutions and chronic populations" has followed an old familiar pattern, with its bumpy rides through inadequate treatment and services, across gaps, absences and omissions?

It is some kind of travesty that more is not done to translate policy and research relating to mental health into practice. In the case of any other illnesses, this would provoke a public outcry. The "ongoing chaotic nature" of our very broken system of mental health care in Australia is evidenced by the fact that "between 2006 and 2012 alone" there have been "50 separate statutory inquiries into different aspects of failure in the [mental health] system" (Rosenberg & Hickie, 2013, p. 2).

The question I leave in the reader's hands for possible future action is, how can we best apply the kind of knowledge acquired from personal accounts such as mine, and translate them into fruitful action?

CODA

My story and my son's, though they are in a sense also disaster stories, serve as a kind of testament to the journey that a contemporary "Everyman" takes through difficult times of personal challenge.

I am mindful that stories of quests for meaning were once told through myth and story, in tales of the young hero's journey and its perils. From the earliest times, myths and stories have indirectly helped children and youth to integrate their own experiences with those of a wider society. However, our contemporary society has all but lost its knowledge of myths.

> Myth, for Roland Barthes, is not a set of stories but rather a format for framing the stories we tell. Modern myths present a version of reality as the truth about reality. If the myth is disseminated effectively, it is normalised and taken to be true. (Barthes, 1972; Corbett, 2017).

Psychotherapist Robert A Johnson bemoans our loss of myth in his introduction to his retelling of *The Fisher King and The Handless Maiden* (Johnson, 1993). He believes the story of Parsifal and the Fisher King, and the story of the miller's daughter, are the two remaining myths useful to modernity. They are about inner suffering, and the loss of feeling – the *anhedonia* spoken of earlier. The Fisher

King symbolises the woundedness of a parent unable to support the next generation. His suffering is profound, his woundedness is deep, and healing can only be brought about if a knight comes to him and asks the right question, whom does the grail serve? But the knight, Parsifal, does not know the right question to ask. A profound woundedness lies at the root of intensely creative people's work, in the opinion of J. D. Salinger's biographer David Shields, there is "just unappeasable hunger, unappeasable sadness and what I would call a wound" (2013). I think my son did not know how to heal his own deep hurt, but his wonderful music or his acutely perceptive writing might have been an avenue for healing work. However, healing him was not my province as a mother. In myths young men definitely leave their mothers behind them! What I hope I am able to do is to bring a healing view of his suffering that is useful to others, to promote change. I hope that I am not judged to have cast blame anywhere, that has not my intention in this thesis, nor have I wished to overwhelm the reader with a litany of regrets or catalogue of mistakes. This thesis is also not an exercise in self-flagellation, nor a means of catharsis for processing my grief, nor a vehicle for apportioning blame at the door of any individual or institution.

> The first task is to take the suffering inside as an interior event. As long as one blames someone outside or holds some institution responsible for the problem, there is little chance of learning or enhancing consciousness. (Johnson, 1993).

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